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**JOANNA SELLER BSc Hons**

**VOLUME 1**

**A STUDY EXPLORING THE PROCESS OF ADJUSTMENT TO  
THE EXPERIENCES OF PSYCHOSIS AND A DIAGNOSIS OF  
SCHIZOPHRENIA.**

**A thesis submitted in partial fulfilment of the requirements of the Open University for the  
degree of Doctor of Clinical Psychology**

**NOVEMBER 2000**

**SALOMONS  
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## **Acknowledgements**

I would like to thank the participants in this study who gave of their time and experiences. I am also grateful to the staff of the Community Mental Health Team, and the day hospital where this research was carried out, who were so supportive of this project, especially Michael Phelan and Kiran Sandhu.

I particularly thank my supervisor, Tony Lavender, for all his help and support with the project, especially his extremely patient explanations of grounded theory methods! Special thanks go to my family and friends who have been so tolerant of my absence, especially my husband, Jonny, who provided food for the body and the soul and received little gratitude at the time – Thank you.

## **ABSTRACT**

A qualitative methodology was used to explore the narratives of participants about recovery from the initial experiences of psychosis, and a diagnosis of schizophrenia. A process of psychosocial adjustment to the experiences of psychosis, and a diagnosis of schizophrenia, appeared central to recovery. The psychosocial impact of a diagnosis of schizophrenia on this adjustment process was also explored. Factors that impeded, or assisted, this process of adjustment were identified.

Semi structured interviews were conducted with 12 participants, six men and six women, who had received a diagnosis of schizophrenia within the last ten years. These interviews were audiotaped, and transcribed, and Grounded Theory was used to analyse the data.

The results formed a temporal stage model of the process of adjustment to the experiences of psychosis and a diagnosis of schizophrenia. Implications for clinical practice and further research are discussed.

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# **1:INTRODUCTION**

## **1.1 Overview**

The concept of recovery from serious mental health problems has been pioneered by the user movement (e.g. Deegan, 1988), and has received increasing interest in recent years from professionals and researchers working in the area of severe and enduring mental disorder (McGuire, 2000). Recovery has been defined by Anthony (1983) as a multi-dimensional concept that does not mean 'cure' but rather the process of a person adjusting to the changes that accompany mental health problems and redefining and redeveloping their life. The aim of this research is to investigate the process of recovery following the experiences of psychosis, and a diagnosis of schizophrenia. By interviewing people who have received a diagnosis of schizophrenia, it is intended to gain an understanding of the process of psychosocial adjustment, and what helps, and impedes, this process.

The introduction will start with a discussion of the concept of schizophrenia and be followed by a discussion of theories of psychosocial adjustment, using research both from mental health and physical health literature. This discussion will include how these theories have been used in clinical practice with people with a diagnosis of schizophrenia. A review of the emerging interest into the individuality of recovery will lead to the rationale for why a qualitative methodology was used to study this phenomenon.

## **1.2 Schizophrenia**

Eugen Bleuler first used the term schizophrenia as a diagnostic label in 1908, and over the past century it has continued to be further developed, and elaborated. This development has led to

the diagnostic criteria used today to define schizophrenia which are found in DSM IV (APA, 1994), and the system most widely used in the UK the World Health Organisation's International Classification of Mental and Behavioural Disorders (WHO, ICD 10, 1992).

ICD 10 (1992) includes a number of symptomatic diagnostic criteria including three forms of delusions (control, influence or passivity); persistent inappropriate delusions; hallucinations (auditory or in any modality when accompanied by delusions or occurring daily for a long period of time); and thought and speech disturbance. These symptoms have become known as the positive symptoms of schizophrenia (Wing, 1989). Other diagnostic symptoms such as social withdrawal, flattened affect and paucity of speech have been described as negative symptoms (Wing, 1989). These symptoms can be experienced together or separately. The requirement for a diagnosis of schizophrenia is;

- A minimum of one very clear symptom of auditory hallucinations, delusions, or thought control (and usually two or more if less clear cut), or
- Symptoms from at least two of the following criteria: the negative symptoms of schizophrenia; hallucinations in any modality when accompanied by fleeting delusions or by overvalued ideas or when occurring daily over a long period; thought disturbance resulting in speech disturbance; and catatonic behaviour.

ICD10 (1992) and DSM IV (1994) are very similar in their description of symptoms, however they differ significantly on the required duration for a diagnosis of schizophrenia. ICD10 requires only one month duration to merit a diagnosis of schizophrenia, and DSM IV requires six month duration. The lifetime prevalence of schizophrenia is nearly one percent, and its annual incidence approximately 10-15 per 100, 000 (Torrey, 1987).

### **1.2.1 Validity and reliability of the concept of Schizophrenia**

“...Schizophrenia appears to be a disorder with no particular symptoms, no particular course, no particular outcome, and which responds to no particular treatment.....” (Bentall, 1990, p.33)

Researchers in the field have become increasingly uncomfortable with the validity and reliability of the concept of schizophrenia (Warner, 1985). Reliability of the use of the diagnostic criteria, DSM IV and ICD 10, has been questioned. Bentall (1990) states a reasonable degree of agreement has been established between the two forms of diagnostic criteria, when applied rigorously in a research setting such as by using the Present State Examination (PSE) (Wing, Cooper, and Sartorius, 1974), to elicit information in order to inform the use of diagnostic criteria. However, it has been questioned how strictly this is adhered to in practice (Lavender, 2000).

Although the criteria may be reliable, the predictive validity of a diagnosis of schizophrenia is poor as it provides little information about prognosis or treatment efficacy. The prognosis of schizophrenia is very uncertain. Ciompi (1980) followed up 289 patients over 65 who had been admitted for treatment for schizophrenia in one hospital at various times throughout the mid to late 1900s. His study found many differences in course and outcome of the disorder. For equal numbers of 228 patients the onset was either acute or insidious. Similarly for equal numbers the course was either episodic or continuous, and outcome was moderate to severe disability in half, and mild disability to full recovery in the other half. A study by Harding, Brooks, Ashikaga, Strauss and Breier (1987) found that one half to two thirds of people diagnosed with a severe mental disorder had significantly improved or recovered twenty to twenty five years after discharge from a psychiatric hospital. Studies like these are changing the traditional perceptions of schizophrenia as a chronic disorder with little hope of recovery (Mcguire, 2000).

Response to treatment has also been difficult to predict on the basis of diagnosis. For example, Crow, MacMillan, Johnson and Johnstone (1986) found only a small proportion of people benefit from neuroleptic medication, even though it is the treatment of choice. A review by Keck, Cohen and Baldessarini (1989) found neuroleptics to be no more effective in treating acute psychosis than sedatives or narcotics, and in some cases a placebo. Neuroleptic medication is also often accompanied by severe side effects, one of the most severe is tardive dyskinesia a neurological disorder involving involuntary movements of muscles, including facial muscles. The incidence of tardive dyskinesia was found to be five percent per year by the American Psychiatric Association (1992). More recently developed anti psychotic medication such as clozapine cause fewer extra pyramidal side effects such as tardive dyskinesia (Meltzer, 1992), and clozapine has been found to be more effective than traditional neuroleptics with negative symptoms (Meltzer, 1995).

There are also difficulties with the construct validity of the criteria that is whether the concept of schizophrenia is internally consistent. If the construct of schizophrenia was internally consistent it would be expected that there would be a high correlation between symptoms and diagnoses, however research such as Slade and Cooper (1979) failed to identify common clusters of symptoms.

However, what is not in question is that a large number of people in this country receive a diagnosis of schizophrenia. The difficulty with the concept of schizophrenia does not negate the value of thinking about the impact of these experiences and of the diagnosis on their lives. This diagnostic label guides most treatment by mental health services. In the year 1993-1994 there was a rate of four per 1000 people in Great Britain given a diagnosis of psychosis (Meltzer, Gill and Petticrew, 1994). Individuals diagnosed with schizophrenia are likely to be suffering from at least one of the symptoms previously described. The symptoms and the

treatment of choice, neuroleptic medication and hospitalisation, will have an impact on their life. The effect of these experiences on their lives, such as, their ability to work and maintain relationships, may also be profound, and it seems important to look at the process of psychosocial adjustment to this effect.

### **1.3 Models of Adjustment**

The experience of an illness can be considered as a life event, which both requires adjustment, and makes demands on a person's resources. An illness affects different dimensions of a person's life, and Derogatis (1986) states that these dimensions are strongly associated with role behaviours (e.g. the vocational role as worker, the domestic role as spouse). When a major event occurs in a person's life such as a serious illness, some of these roles can be lost or changed. In order to function optimally, adjustment to these new or changed roles has to take place.

There are two main models of adjustment, these are descriptive and process models. Descriptive models have mainly been used in mental health services to provide an explanation of the social factors involved in schizophrenia, and to inform assessment and treatment. The process models discussed here, have come from two main areas, cognitive theories of attribution, and models of grief and loss. These process models describe in more detail the psychological processes involved in adjusting to the experience of a disorder.

#### **1.3.1 Descriptive models and measures of adjustment**

Descriptive models of adjustment to schizophrenia mainly arose from an increasing awareness of the psychosocial impact of having a mental disorder, and the relationship of that impact to the course and outcome of the disorder. Wing and Morris' (1981) model has been one of the

most influential models in the field of psychiatric rehabilitation. They defined three levels of 'disability' arising from a severe and enduring mental disorder. These were:

- Primary handicap – The symptoms of the disorder itself.
- Secondary handicap – Adverse personal reactions to the disorder.
- Tertiary handicap – Social disadvantages resulting from the experience of the disorder.

Wing and Morris (1981) stated that it was not only the disorder that was disabling but also the social disadvantages accompanying it such as stigma and poverty, and the psychological reaction to the disorder. They suggested that the above three 'handicaps' led to social disablement, in essence a situation in which the individual was unable to perform socially to the standards they expected of themselves, or to those they were expected to perform by others. This theory has been used to inform assessment and treatment in psychiatric rehabilitation through its focus on social functioning.

The shifting focus towards social functioning encouraged the development of measures to assess at single points in time, clients' levels of social functioning and adjustment. In 1981 Weissman, Shalomskos and John reviewed eight tools measuring social adjustment that had been devised over the preceding six years. Since then 'Quality of Life' measures have been used increasingly to assess both the impact of the disorder on a person's life, and the efficacy of interventions (Oliver, Huxley, Bridges and Mohamad, 1996). Felce (1997) defined Quality of Life as made up of three variables:-

- Life conditions – The objective description of individuals and their circumstances.
- Subjective wellbeing – Personal satisfaction with the above life conditions.
- Personal values/aspirations – The relative weight which an individual attaches to the above two variables.

These measures have been used to assess level of adjustment at single points in time, but they have not been designed to provide information on the process of adjustment. The descriptive models of adjustment have provided an explanatory framework, have led to practical advances in psychiatric rehabilitation, and increased the focus on social factors involved in severe mental disorder. However, they have also not provided information about the actual process of adjustment to a mental disorder.

The descriptive models of adjustment to schizophrenia have led to practical recommendations for services, and demonstrated the importance for services to be needs led. However, they have not led to a focus on assisting people through the process of adjustment. In fact, psychologists such as Goodwin (1997), have argued that psychiatric rehabilitation's attention to immediate need has mitigated against more theoretical development of what is involved in the recovery process, and how it can be assisted. Perkins and Repper (1996) suggested that the skills based approach, common in psychiatric rehabilitation services, which acts to identify skills deficits (e.g. social skills, budgeting), does not take into account the grieving process which may have a drastic effect on people's ability to use their own skills.

### **1.3.2 Process models of adjustment**

There has been a lack of research investigating the recovery process in mental disorder (Drayton, Birchwood and Trower, 1998) therefore this section draws partly on research from physical health literature to explain the process of adjustment or adaptation to illness. Process models have come from two main areas, cognitive theories of adjustment, and theories of grief and loss.

### **1.3.2.1 Cognitive Theory of the process of adjustment**

Cognitive theory argues that adjustment depends on the attitudes, beliefs and thoughts people have about themselves and the events in their lives (Beck, 1976). For example, in common with other cognitive models Taylor's (1983) Theory of Cognitive Adaptation outlines three factors central to adjustment to illness:

- i. the use of causal attributions in the search for the meaning of an event;
- ii. attributions of control over the event;
- iii. enhancement of self-esteem.

#### **i. Causal Attributions**

Attribution theory (Weiner, 1986) maintains that following a threatening event people will make attributions, thoughts or beliefs that make sense of or explain a phenomenon, to understand what has happened. Cognitive appraisal of illness involves a number of types of attribution, and particularly important to adjustment are attributions about the cause of the illness (Sensky, 1997). Research into the role of causal attribution in adjustment to illness has mainly been carried out in the physical health field. Kelley (1967) outlined that people make causal attributions using a scientific approach. This suggests that people search for an accurate cause. However, Sensky (1990) states that much of the research has focused on situations in which people make 'inaccurate' causal attributions. However, these are categorised as 'inaccurate' from a medical model, but they hold meaning, and may be 'accurate', for the person concerned.

Sensky states that one of the aspects of forming a causal attribution is determining whether the cause is internal or external. He explains that when first faced with an illness most people initially search for an environmental cause, something external to them. If this is not found, it



is only then that people search for an internal cause. One of the ways of attributing causes externally, which is particularly salient for serious illness, is blaming others. Initially this may be functional for the person, as by externalising blame it can shift responsibility away from the person, giving them time to re-evaluate their own role, and accept responsibility gradually. However, in some circumstances, and if it goes on for a long period, it can be dysfunctional, for example hindering an individual's ability to utilise support. It has also been suggested that blaming others reduces individuals' ability to use effective coping strategies, and a link has been found between blaming others and poor adjustment (Tennen and Affleck, 1990).

Research looking at self-blame has yielded disparate results. For example in breast cancer, some studies have found it to be adaptive (Timko and Janof-Bullman, 1985), but other studies have found it is dysfunctional for adjustment (Houldin, Jacobsen and Lowery, 1996). Self blame has been described as adaptive because by taking some responsibility, people may feel more in control of events in the future (Timko et al., 1985). However, in other situations, perhaps where the disorder has a chronic course it is more important to look forward, and to make sense of the current situation, than to look back and make causal attributions (Sensky, 1997).

There is a distinction between making attributions about the cause of the illness, and the belief that one can control its symptoms. Lay theories are important here, Sensky (1997) suggests that beliefs about illness commonly reflect lay theories, and these may be dysfunctional. For example, there is sometimes an implicit assumption that beliefs about control can be inferred from causal attributions, that is if a cause is known then the illness can be controlled. However this is not the case, such as, in diabetes, where the cause is unknown, yet it is successfully controlled in most cases. It may be that beliefs about cause although 'not true' according to the medical model can still act to enhance a sense of control.

## ii. Attributions of controllability

Taylor (1983) described the second factor important in adjustment to physical illness as the attributions individuals make about the amount of control they have over their disorder. She discussed the significance of control in gaining a sense of mastery over the situation, which may aid adjustment. Birchwood, Mason, Macmillan and Healy (1993) also suggested that the psychological reaction to a mental disorder is affected by its perceived level of controllability. They stated that depression in schizophrenia could be a psychological response to an apparently uncontrollable life event and its disabilities. There has been found to be a high level of co-morbidity between schizophrenia and depression. For example, in a review of depression in schizophrenia by Siris (1991) morbidity ranged from 20% to 45%. Birchwood et al. (1993) found that lower perceived control of the illness, and an external locus of control (a belief that events are caused by external factors), was linked to depression in individuals with psychosis.

Brown, Harris and Hepworth (1995) studying depression in women, found that appraisal of a life event was particularly salient when the event involved loss, or threat and was appraised as humiliating or entrapping. Rooke and Birchwood (1998) using elements from the Brown et al. study, found that the feeling of a lack of control in psychosis was so strong that it could be perceived as entrapment (e.g. enforced hospitalisation, medication) and they found feelings of entrapment to be linked with depression.

## iii. Self Esteem

Taylor (1983) suggested a crucial part of the process of adjustment was the gradual enhancement of self-esteem, after it had been lowered by an event. She explained that in a serious physical illness, one of the ways of enhancing self-esteem is through social comparison processes. In essence people attempt to compare themselves favourably with others in order to

enhance their self-esteem. However, the stigma associated with a diagnosis of schizophrenia seems to mitigate against the use of this process to enhance self-esteem. A recent MIND survey, Counting the Cost (Baker and MacPherson, 2000), highlighted the added burden that stigma places on the emotional well being of people who have experienced mental health problems. They found that the main source of stigma was from media coverage, and that this media coverage had a negative effect on 50% of users' mental health, with a third saying that it made them feel anxious and depressed.

This suggests that increasing self-esteem might be difficult if the diagnostic label of a mental illness were accepted. Warner (1985) argued that a person's sense of self worth and competence will experience cognitive dissonance when faced with a diagnosis of mental illness with its associated stigma. In essence that a person's sense of self worth will be compromised by the devalued position that a diagnosis of mental disorder places them in, within the current society, making it more difficult to build self-esteem. Warner, Taylor, Powers and Hyman (1989) found that people who accepted a diagnostic label of mental illness exhibited lower self esteem, if they also perceived high levels of stigma attached to the mental illness. Those who rejected the diagnostic label of mental illness had higher self-esteem generally. The acceptance of a label of mental disorder has also been linked to depression in psychosis (Birchwood et al., 1993).

#### **1.3.2.2 The Cognitive Model of Recovery style**

McGlashan, Levy and Carpenter (1975) proposed that people recovering from psychosis adopt one of two distinct 'recovery' styles. Similarly, Wing and Morris' (1981) outlined two types of psychological response to mental health problems described as dysfunctional: -

- The person finds the idea of having a mental health problem extremely frightening, and copes by denying any problems at all. Taylor and Perkins (1991) found that 50% of psychiatric inpatients denied having any mental health problem.
- The opposite response is that the person may be so frightened of exacerbating the problems and so desperate to prevent relapse that they lose all confidence, and avoid all stress. This then becomes a negative cycle, where the less they do, the less they are able to do.

However these two responses are not mutually exclusive, and Repper and Perkins (1996) suggest that it is common for people to move between these perspectives. McGlashan et al's work extended beyond these responses into two recovery styles identified by the Integration/Sealing Over scale (1987): -

### **Integration**

In an integrative recovery style people are aware of the continuity in their own self from before the illness, through the psychotic episode, and during the time of recovery. They are able to take responsibility for the psychotic experiences, and can recognise the differing, and perhaps opposing, aspects of the experiences (e.g. pleasurable and painful). It is suggested individuals with this recovery style are able to be curious about their experiences, use their experiences positively to help themselves, and also able to use others to help them understand their experiences.

### **Sealing over**

In the sealing over recovery style the psychotic experience is isolated and viewed as an interruption to life. The cause is believed to be external to the person, and there is no desire for any investigation of the symptoms. In this style although people are aware of the negative aspects of their psychotic experience, they resist engaging others to explore them. Sealing over

describes a process by which psychotic events are isolated from non-psychotic events by a process of both conscious suppression and repression.

Mcglashan (1987) found better functioning in people with severe mental illness, with an integrative recovery style. However, people with a diagnosis of schizophrenia and schizoaffective disorder tended towards a sealing over recovery style. Drayton, Birchwood and Trower (1998) found that co-morbidity of depression and schizophrenia was significantly associated with a sealing over recovery style.

One difficulty with these categorisations of recovery styles is that they seem to indicate a 'right' way to recover. Mcglashan's work in particular assumes that there is one acceptable view of reality (Beck-Sander, 1998). This is indicated by the terms used to define the recovery styles, such as an 'awareness' of continuity through the psychotic experience, described in the integrative recovery style. In the sealing over style people are described as not having this awareness, and viewing the experience as an isolated incident, quite separate from the rest of their life. Implicit within this assumption is that there is a 'right' and a 'wrong' way to make sense of experiences. It also does not allow for the holding of multiple perspectives as stated by Repper and Perkins (1996) earlier. This model seems to suggest that an acceptance of a diagnosis of mental illness, is an important part of the recovery process, but as discussed earlier this can lead to lowered self esteem and depression.

### **1.3.2.3 Models of Grief and Loss**

Chronic illnesses can result in many losses, including loss of role, and loss of relationships; adjustment to these losses can be conceptualised using the grief process. The grief process is generally described within stage models although most theorists agree that these stages do not

necessarily occur consecutively. For example, Kubler-Ross (1969) divides the grief process into five stages: -

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance.

Although this was originally written for people facing death, it has been used as a model to describe reaction and adaptation to different types of major loss, associated with illness and disability (Wortman and Silver, 1989).

Lindgren, Burke, Hainsworth and Eakes (1996) argued that the grief process does not fully explain the reaction to the experience of loss in chronic illnesses. In chronic illnesses, there are often continual losses over the duration of an illness or disability and the experience of grief resulting from these has been termed chronic sorrow. Lindgren et al. define chronic sorrow as a grief that occurs in a cyclical pattern of resurging feelings of sorrow interspersed with periods of calm. They also point out an important distinction between grief after bereavement, and grief during the course of an illness, in that resurgent grief feelings after bereavement tend to abate over time, but in chronic sorrow they can increase in intensity. The main attributes of chronic sorrow are: -

1. A perception of sorrow over time in a situation that has no predictable end.
2. The sadness is recurrent.
3. The sadness can be triggered internally or externally, and brings to mind the person's losses, disappointments or fears.
4. The sadness is progressive.

This concept has been used to understand the impact of chronic physical illnesses such as Multiple Sclerosis (MS). Hainsworth (1994), in a study with people with MS, found that sorrow was triggered by feelings of loss of control; comparing themselves to healthy peers; remembering how it had been before their illness; and acknowledgement of the control MS had over their life.

The grief model, and the chronic sorrow model are quite different from each other. Implicit in the typical model of grief and loss in response to an illness, is the 'working toward' adaptation or recovery from the psychological impact of the illness. The model of chronic sorrow does not suggest something that can be resolved, in fact it suggests a worsening picture of psychological distress over time. As schizophrenia can be experienced as a chronic disorder it may be that the chronic sorrow model is more appropriate than the grief model to describe the psychological reactions involved.

### Grief and loss and schizophrenia

Appelo, Slooff, Woonins and Carson (1993) suggested close parallels between the grieving process, and adjustment to a diagnosis of schizophrenia. They compared the concepts and processes of grief and schizophrenia using Wing and Morris' impairment theory (1981) to elaborate this relationship. As discussed earlier this theory looks at social disablement seeing this as not just a function of the person's mental health problems, but also their responses to mental health difficulties, and the social disadvantages that accompany these difficulties.

Appelo et al. (1993) argued that the primary impairment of schizophrenia involved many losses: loss of cognitive functioning; social relationships, roles and positions; and different behavioural and emotional functions, and the secondary impairments also generated a sense of loss. Strauss, Rakfeldt, Harding and Liberman (1989) suggested that psychological reactions

to schizophrenia, such as, loss of hope and self-esteem, problems in finding a new identity, and a feeling of guilt for past dysfunction, could result in, or exacerbate, negative symptoms. Appelo et al. proposed that the depression often suffered by people with a diagnosis of schizophrenia was part of the grief process, and that the secondary impairments in schizophrenia could be understood as grief reactions to loss. Rooke and Birchwood (1998) found that psychosis by limiting activity in the interpersonal and achievement domains, led to a loss of valued roles or goals, and that particularly the loss of social role was linked to depression. Perkins and Repper (1996) similarly compared adapting to the experience of serious ongoing mental health problems to a bereavement process: "Lamenting the loss of a life that one had or expected to have and coping with the challenge of building life afresh in a society where one is stigmatised and often excluded." (p.21)

### **1.3.3 Summary of process and descriptive models of adjustment**

It seems that the theories of attribution and cognitive appraisal in relation to adaptation to schizophrenia, are based on research evidence. However, there has been little research completed on the role of grief and loss in schizophrenia. This has mainly been discussed theoretically, and seems to stem more from observation in clinical practice.

Both descriptive and process models of adjustment have been used to inform clinical practice. Cognitive theories of adjustment to psychosis have led to recommendations for intervention. For example, Birchwood et al.'s (1993) finding of the importance of attributions of control supports the use of the 'psychotherapeutic model' with people with schizophrenia. They describe this model as working to encourage blame free acceptance of the illness, and efforts to develop a sense of mastery over it, for example with the use of Cognitive Behavioural Techniques to manage symptoms (Tarrier, 1994).



However, this does not mean that more traditional rehabilitation functions with their roots in descriptive models of adjustment are not helpful. Mcglashan's (1987) work differentiating between recovery styles suggests that intervention should be tailored to the recovery style of the person. He suggests that 'integrating' clients may prefer the psychotherapeutic model, whereas 'sealing over' clients may be more amenable to interventions such as skills based approaches that do not require an exploration of the meaning of the illness.

Although there has been little research on the models of grief and loss in schizophrenia they are increasingly being used to inform clinical practice. Appelo et al. (1993) proposed that the central components of rehabilitation should be acceptance and reactivation. This seemed to suggest a combination of the psychotherapeutic and skills based models, including a focus on the importance of the grief that may be being experienced. Perkins and Repper (1996) in their book "Working Alongside People with Mental Health Problems" incorporate the importance of grief within their recommendations for interventions. They state that support offered by mental health services should include two main elements:-

- Providing people with the time and opportunity to grieve, to express their anger, fear and hopelessness enabling the person to realistically appraise their mental health problems.
- Encouraging a rebuilding of their life by identifying strengths as well as problems and providing support to build and maintain a realistic expectation of themselves.

However, these models assume generalisability between individuals, and recovery is increasingly being seen as an individual process.

#### **1.4 Individuality of recovery**

Over recent years increasing attention has been given to users' reports of their own experiences (Chadwick, 1997). Groups such as MIND and The Hearing Voices Network have been

instrumental in the use of the term recovery to describe the process of adjustment after a diagnosis of schizophrenia. Patricia Deegan (1988) states “Recovery refers to the lived or real life experience of people as they accept and overcome the challenge of the disability.”

The individuality of the process has emerged from these real life descriptions of recovery. Chadwick (1997) suggests that this individuality of the recovery process should be studied using a combination of quantitative and qualitative approaches, aiming to produce a person rather than a symptom orientated approach to rehabilitation by mental health services.

Although the recovery process is individual there has been some effort to define what it involves. Anthony (1993) outlined nine principles of the recovery process:-

1. Recovery can occur without professional help, it is the user who recovers.
2. Recovery requires the presence of people who will believe in and stand by the person.
3. Acceptance of a recovery view is not a function of a particular definition of mental illness (e.g. social, biological).
4. Recovery can occur even though symptoms are still present or reoccur.
5. Recovery changes the frequency and duration of symptoms.
6. Recovery involves steps forward and back.
7. Recovery from the consequences of mental illness such as poverty can be more difficult than recovery from the illness itself.
8. Recovery from mental health problems does not mean they did not exist.
9. Other people who have recovered or are recovering from mental illness are sources of knowledge about the recovery process.

These principles are supported by individual accounts of recovery such as Coleman (1999) who talks of the value of people who believed in him. In writing about his Support Worker he

says: “It was her who saw beneath my madness and into my potential, it was her faith in me that kick-started my recovery and it is to her I owe an enormous debt.” (p.13, 1999)

One of the ways that these insights into the recovery process have been operationalised is through the use of narrative therapy in the recovery process. White (1987) uses this therapy to enable the person to construct a story or narrative in order to understand themselves and to rebuild their sense of identity and role.

## **1.5 Rationale for study**

### **1.5.1 Rationale for researching Adjustment**

The aim of this research was to extend the understanding of adjustment to mental disorder, by focusing on individuals’ experiences of recovery from the experiences of psychosis, and a diagnosis of schizophrenia. Although studies have addressed psychosocial adjustment to schizophrenia, most studies have used measures of social functioning to assess adjustment to schizophrenia, rather than looking at the actual process (e.g. Huguelet, Zabala, Cruciani and Binyet, 1995). Process models of adjustment and recovery have mainly come from clinical observation, and research has focussed on specific aspects such as controllability. Research has described specific recovery ‘styles’, but these do not seem to take into account the variability between individual recovery processes, which is increasingly emerging from data from the user movement. There is limited research relating the global impact of a diagnosis of schizophrenia to the process of recovery.

It is currently not known whether the models suggested for adjustment to physical disorder apply to mental disorder. Mental disorder, specifically schizophrenia, carries with it inherent

differences to physical disorders that could affect adjustment. As discussed there is a difficulty with the validity of a diagnosis of schizophrenia. This means that people with this diagnosis are not a homogenous group, and the experience of each may be very different, therefore, making it extremely difficult to generalise about impact and recovery. The rigidity of current theoretical accounts may not allow for individual variability, and also do not account for the nature of this variability. Another major issue with schizophrenia is how the actual disorder affects the psychological process of adjustment. The actual symptoms of schizophrenia such as disordered thinking may affect the psychological processes of adjustment that have been studied with physical disorders. There is also the further complication of the stigma associated with schizophrenia, and how this affects psychological adjustment. All of these reasons made it desirable to explore individual accounts of recovery to examine the psychological processes that emerge.

This research thus aims to provide an understanding of the process of psychosocial adjustment in individuals with a diagnosis of schizophrenia, and what assists this process. It is hoped that the research will help to inform service provision, and professionals working with this client group.

### **1.5.2 Reasons for qualitative methodology**

The aim of this research was to gain a detailed description of the recovery process from the experiences of psychosis and a diagnosis of schizophrenia. The richness of the data and the individual variability inherent in recovery with this population meant that a qualitative approach that would address both these aspects appeared the most suitable option.

The method involved interviews about the subjective experience of recovery from psychosis. As the data generated from the interviews was descriptive in nature, and to enable complex aspects of experience to be studied, a qualitative method was used to describe and analyse the data. Charmaz (1995) states that qualitative methods are specifically appropriate for studying individual processes, interpersonal relations and the reciprocal effects between individuals and larger social processes. A qualitative methodology meant that the impact of psychosis on a variety of life domains could be addressed rather than using standardised measures that would limit the focus to specific areas. Orford (1995) similarly states that qualitative methods are particularly useful for studying complex events that take place in a real life context.

Qualitative methodology aims to come to an understanding about the meanings of experiences from the perspective of the people being studied. Quantitative methods generally aim to measure an objective reality that can be generalised. However, qualitative methods come from a base of accepting that there may be many 'realities' that hold true for different people in different circumstances, and these can be equally valid. Traditionally the amount of 'truth' ascribed to this 'reality' depends on the power of the person whose 'reality' it is (Foucault, 1965). The decision to study the concept of recovery which itself comes from the user movement, a movement which traditionally does not have much status or power, and the previously discussed individuality of the recovery process led to a decision to use an approach which acknowledges and encourages different realities.

### **1.5.3 Reasons for Grounded Theory**

Grounded Theory (Strauss and Corbin, 1998) is a methodology consisting of data collection and analytic procedures which aims to develop theory. It comes from a phenomenological base which assumes a relationship between what a person says, and the psychological constructs that they hold (Giorgi, 1995). It therefore seemed appropriate for this study as interviews used

people's narratives of recovery, with the aim of using this data to come to an understanding of the psychological processes involved in adjustment.

Grounded Theory has been found to provide a coherent method for qualitative data collection and analysis (Henwood and Pidgeon, 1995). It also includes within it rigorous procedures to check, refine and develop ideas about the data (Charmaz, 1995). It is suitable for this study because the aim of this research was to generate a theoretical account of the process of adjustment to, the experiences of psychosis and a diagnosis of schizophrenia. The theoretical account will be based on descriptions of individuals' personal experiences, and grounded theory provides an inductive approach to generate this theoretical account from the data.

## **1.6 Research Questions**

The aim of the research was to develop a theoretical account of adjustment in the process of recovery from, the experiences of psychosis and a diagnosis of schizophrenia. The specific questions that the research was designed to address are:-

1. What is involved in the process of adjustment?
2. How does the psychosocial impact of a diagnosis of schizophrenia relate to the process of adjustment?
3. What aids or impedes this process of adjustment?

## **2: METHOD**

### **2.1 Design**

The study used a cross-sectional, within group design, to investigate the process of adjustment to, experiences of psychosis and a diagnosis of schizophrenia. Given the exploratory nature of the study a qualitative methodology was used to analyse the data, in the form of Grounded Theory (Strauss and Corbin, 1998).

### **2.2 Participants**

Twelve participants were selected, all with a formal psychiatric diagnosis of schizophrenia within the last ten years. The sample was made up of six women, and six men. The sample was drawn from the Service users of a multi disciplinary Community Mental Health Team (CMHT), and a day hospital, which provided services for people with severe and enduring mental health problems.

#### **2.2.1 Sampling**

Simultaneous involvement in data collection and analysis phases of research is a crucial part of Grounded Theory (Charmaz, 1995). Therefore, this study was carried out in two phases. In the first phase, six men were interviewed. The narratives generated from these interviews were subjected to some initial analysis using the procedure of open coding described later. The ideas emerging from this initial analysis were incorporated within further interviews, and to engage in theoretical sampling. This meant looking at different participants from this population in order to look at how the properties of concepts vary in relation to different dimensions. The second phase consisted of interviewing six women to check and refine the emerging conceptual categories. Their narratives were analysed using the same procedures

with constant comparison to the first sample, and then theory development was completed using the analysis of all interviews.

### **2.2.2 Selection Criteria**

All participants met the inclusion criteria outlined below:-

1. A current psychiatric diagnosis of schizophrenia.
2. A diagnosis of schizophrenia within the last two to ten years.
3. HoNoS score – Hallucinations and delusions classified as mild, moderate or severe clinical problem.

The following exclusion criteria were applied:

1. Presence of organic brain disease.
2. Clients who did not understand the study and were unable to give informed consent.

### **2.2.3 Health of the Nation Outcome Scale (HoNoS)**

The Health of the Nation Outcome Scale (Wing, Beevor, Curtis, Park, Hadden and Burns, 1998) was used to ensure that the symptoms commonly associated with schizophrenia were present in this sample. This 12 item scale (Appendix 1) was designed to measure the health and social functioning of people with mental health problems. Examples of areas covered are hallucinations and delusions, social relationships and aggressive behaviour. Problems are rated from zero to four, where zero is no problem and four represents a severe clinical problem. Each aspect of the individual's functioning is rated only once and the rater is asked to concentrate on the most severe problem in each category. Four sub-scores and a total severity score are obtained. For the purpose of this study, the total score did not include items 11 and 12 as these items provide a measure of the service provided.



The development of the scale occurred in four phases; two pilots, a field trial and analysis of the structure. Checks were made on the acceptability and structure of the scale. Test-retest reliability correlation coefficients for all items fell between 0.74 and 0.88, except aggression (0.61). The Brief Psychiatric Ratings Scale (Overall and Gorman, 1962) and the Role Functioning Scale (Goodman, Sewell and Cooley, 1993) were used to evaluate comparative validity; the resultant product moment correlation was 0.65. Sensitivity to change was demonstrated through comparisons with retrospective clinical judgement. The final version has proved to be simple to use, is of acceptable reliability, is compatible with other well-established instruments and is clinically acceptable.

#### **2.2.4 Characteristics of the Participants**

Demographic details of participants' are summarised in table 1. Male participants mean age was 25, and female participants' mean age was 33. The overall mean age of the sample was 29 years. The mean HoNoS score for men was 10, and for women was 7. The overall mean HoNoS score was 8.5. All participants had had at least one admission to hospital for psychosis. The mean time since diagnosis for men was 4.5 years and for women was 5 years, with an overall mean of 4.8 years.

**Table 1: Demographic characteristics of sample**

Participant	Sex	Age	Ethnic origin	Living situation	HoNoS score	Time since diagnosis
1	Male	24	UK Black	With Parents	2	2 years
2	Male	28	UK White	Mental Health Hostel	18	8 years
3	Male	26	UK White	In patient	18	8 years
4	Male	27	UK White	With mother	4	3 years
5	Male	22	UK White	With mother	8	4 years
6	Male	24	UK Asian	With parents	11	2 years
7	Female	20	UK Asian	With parents	7	2 years
8	Female	38	UK White	Alone	8	8 years
9	Female	36	UK White	Alone	7	6 years
10	Female	23	UK Black	Alone	6	6 years
11	Female	41	UK White	With son	6	3 years
12	Female	39	UK Black	Alone	7	6 years

## **2.3 Measures**

The aim of the interviews was to generate a narrative from the participants about the process of recovery from psychosis. In order to elicit the information a semi-structured interview schedule was developed (Appendix 2).

### **2.3.1 Development of the Interview Schedule**

The interview schedule was devised using suggestions from Smith (1995) as an initial guide. After reading the relevant literature, and considering the research questions a list of main areas of experience that needed to be covered was drawn up, and questions that addressed these areas were developed. This schedule was then read by a Clinical Psychologist working within the field, and revised to include specific prompt questions if the general questions did not elicit a 'rich' response.

### **2.3.2 Piloting the Interview Schedule**

The interview schedule was piloted on a mental health professional who role-played a client. Following this, it seemed appropriate to use questions to draw out a narrative or life story from the individual about their experience of psychosis, and this would include many of the areas to cover on the interview schedule. The interview schedule was then slightly revised to incorporate this more effectively. It was then piloted on one participant, and further revised, so that the initial questions were more about what had happened, and questions about thoughts and feelings surrounding those events came later, in order for rapport to be built and trust established.

### **2.3.3 The Interview Schedule**

The interview was semi-structured and not standardised (Appendix 2), as the aim was to encourage participants to talk in an open and honest way with the interview following their concerns. The interview was divided into eight sections broadly following a temporal format.

#### **Section 1: Initial Information**

This covered information about current circumstances, for example age, living situation, and current nature of experiences.

#### **Section 2: Experience prior to diagnosis**

This aimed to elicit information about when and how the participant first recognised any symptoms and the meaning they gave to them, and the roles played by other people at that time.

#### **Section 3: Contact with services**

This aimed to elicit a narrative describing how they came into contact with mental health services, and their response to these experiences.

#### **Section 4: Diagnosis**

This covered how communication of the diagnosis, and the sense they made of the diagnosis.

Also, what was and was not helpful, as well as what would have been helpful, at the time.

#### **Section 5: Impact on life**

This covered main areas of life including work, relationships and living situation. It also asked about how they considered things would have been different without a mental health problem.

### **Section 6: Impact on self**

This covered how participants had attributed meaning to different experiences of psychosis, and the feelings associated with those experiences. It also looked at how they coped with them, and the role of others in that.

### **Section 7: Experiences of services**

This covered their views of their experience of services.

### **Section 8: Debriefing**

Participants were asked about their experience of participating in the interview, and whether it had raised any issues for them. They were also asked if they had anything further to add, or questions to ask.

## **2.4 Procedure**

### **2.4.1 Ethical Considerations**

The design of the research was in accordance with the British Psychological Society's Ethical Principles and Guidelines (1998), and the Division of Clinical Psychology Professional Practice Guidelines (1995). An application was made to the Trust's research ethical committee and permission was obtained to carry out the study (Appendix 3). Pertinent ethical issues are dealt with as they arise during discussion of procedures.

### **2.4.2 Recruitment Procedure**

The research was carried out in a mental health trust in which the researcher had worked previously. A Consultant Psychiatrist who worked within a Community Mental Health Team (CMHT) within the Trust agreed to be the contact person for the research, and liaised with the team to enable the researcher to attend the weekly CMHT meeting, where the study was

explained and discussed. Members of the team were asked to identify clients that they keyworked from their caseload, who they considered were eligible to participate in the study. This method elicited eight participants, but the criteria of time since diagnosis limited the possible sample, and the remaining four participants were recruited from the adult mental health day hospital in this trust after contact with the manager and professionals working within that service.

#### **2.4.3 Briefing Procedure**

An information sheet was developed (Appendix 4) outlining: -

1. The nature and purpose of the research, and what participation would involve. This stated that, with permission, the interview would be audiotaped.
2. Confidentiality, that all material would be held in confidence and used for research purposes only. Audiotapes would be listened to by the researcher and supervisor, and would be erased. Also, that although their views would be written up, they would be anonymised.
3. The right to withdraw at any time with no impact on the level of service they received.

#### **2.4.4 Initial Contact**

Clients were initially approached by their Keyworker, who gave them the information sheet and discussed the study with them. If they were interested, a meeting was arranged between the participant and the researcher. The information was again discussed at this meeting; participants were encouraged to ask questions and the researcher clarified any areas of confusion. The rationale for tape recording interviews was discussed, and their right to refuse permission for recording was raised. Participants were informed that the tapes would be erased after transcription, and transcripts would be destroyed after one year. If they continued to express an interest in participating, they were asked to sign a consent form (Appendix 5).

Interviews and meetings were mainly arranged at the CMHT base or at the day hospital when the client would be attending anyway. Some interviews were carried out at the participant's current accommodation, which included a hospital ward, a mental health hostel, and one participant's own home, this was at participant's specific request.

#### **2.4.5 Format of Interviews**

Before starting the interviews, participants' attention was drawn to the information sheet and they were asked if they wanted clarification on any aspect of the study. The interview then commenced, and lasted from forty to eighty minutes.

The format of the interview depended on the participant. With some participants a narrative approach was used, where participants generated a 'story' about their experiences with some prompts from the interviewer to ensure all areas of the semi structured interview schedule were covered. However, other participants required a more structured approach, and the semi structured interview format was followed more closely.

After each interview, participants were debriefed and any concerns addressed. The participant's Keyworker was informed (with their permission) if they requested any additional support. If participants found the interview distressing more time was spent debriefing and their Keyworker was informed (with their permission). Participants were informed that they could contact the researcher if they had any additional questions. Two participants were asked, after the interview, if they would be willing to give feedback on a written summary of the results and they consented verbally.

## **2.5 Data Management**

Grounded Theory is a methodology for developing theory from data that is systematically gathered and analysed throughout the research process. This study used procedures of Grounded Theory from Strauss and Corbin (1998). Data from the interviews was analysed using the software programme for qualitative data analysis NUD.IST. The analysis consisted of three stages:-

### **2.5.1 Open Coding**

The first step was transcribing the interviews from tape, and labelling the transcripts (e.g. date, participant number, and participant details). During transcription ideas were noted in the research diary to make the process as transparent as possible. After transcription, a detailed reading of the data took place, again with ideas being noted. At this stage, microanalysis or line by line coding of three transcripts took place to generate initial codes. This involved examining text, and defining what was happening or represented there by asking questions of the data, following procedures for this outlined by Strauss and Corbin (1998), and developing a code to represent this understanding. The size of the segments of text varied. Sometimes a code was developed for a single sentence, elsewhere a code was applied to a whole paragraph.

Constant comparisons were made between text and codes, and segments of text that contained further examples of this particular code were noted. Links with other codes were also noted in memos. Further transcripts were analysed using these codes, paragraph by paragraph, and further codes generated. At this stage, segments of text unrelated to the research questions were discarded.

This stage included the generation of categories and sub categories. Initial categories were defined by the three research questions, and codes were placed within these categories during the initial coding stage, and some in more than one category. Once in these categories the process of categorisation involved looking for codes that appeared numerous times, and codes that seemed to fit into sub categories and these were generated, alongside more developed categories. This was achieved by defining the codes according to their component properties, and the dimensions along which these properties varied. This process used memos that had been written over the whole process. Memos were written descriptions of the researcher's thoughts, interpretations, and ideas, which were written in the research diary, or attached to specific segments of text, and memo writing continued throughout the process of interviewing, transcribing, and analysis.

### **2.5.2 Axial coding**

Strauss and Corbin (1998) described this process as the 'putting back together' of the data after it has been broken down by open coding. This was completed using the paradigm organisational scheme suggested by Strauss and Corbin, to define the relationships between the sub categories and categories. This involved relating categories to each other to form components of the paradigm. However, open and axial coding were not performed sequentially. Some open coding was carried out before axial coding could begin, but open coding continued alongside axial coding to continue to define properties and dimensions of categories.

### **2.5.3 Selective Coding**

This was the process of integrating and refining the categories to form a theory. This involved choosing a central core category, which all major categories related to, that constituted the



main theme of the research. The procedures outlined by Strauss and Corbin for identifying the core category, and relating all the categories to it were used such as writing a 'storyline' that encapsulates the main theme of the data. The theory was then refined using diagrammatic representations to link categories together.

## **2.6 Validity and Reliability Issues**

In quantitative research, reliability and validity have been used to assess scientific rigour. Reliability has been defined as the replicability and consistency of the findings, and validity as the apparent 'truth' of the findings. In qualitative research there is not considered to be an absolute 'truth', rather multiple truths, that will apply to different people at different times in different circumstances. In this study the results are not expected to be generalisable, rather the aim was to develop an explanatory framework of the adjustment process in this sample and develop ideas that could be tested further, perhaps using quantitative methods. The requirement therefore when using qualitative methods is for the research to be relevant, and to provide a plausible and useful understanding of the subject being studied (Elliott, Fischer and Rennie, 1999). Validity and reliability, the scientific rigour of qualitative research are therefore assessed using different strategies. The following procedures suggested by Smith (1995) were therefore followed:-

### **2.6.1 Auditability**

This means that the research process should be transparent, to enable another researcher to follow the steps that led to the final report. It is not aimed that if they followed the steps they would come to the same results, as qualitative research is very much about the interplay between the specific researcher and participants. This encompasses the tenet of reflexivity, being open about the process of the research and any influences on it such as the researchers own beliefs and biases. In order to address this a research diary was kept, which mainly

included reflections on the research process, and detailed how decisions were made about the process that was followed (e.g. methodological decisions) (Appendix 6).

In order to aid auditability of this study a list of the codes and categories generated by the analysis was included in appendix 7, and an example of quotes and codes that made up one of the categories was included in appendix 8. A full interview transcript was included in appendix 9, and a brief excerpt from a transcript with coding was included in appendix 10.

### **2.6.2 Respondent Validity**

Respondent validity (Henwood and Pidgeon, 1995) aims to elicit the views of participants on the researcher's interpretations. It is also part of the commitment of qualitative research to democratic research practices. It acts to provide multiple viewpoints on the data, and perhaps to elaborate on emerging theory. In this case, towards the end of data analysis, a written summary of the emerging model was sent to two participants, with a stamped addressed envelope, and their opinions and views requested in written format.

### **2.6.3 Inter rater reliability**

Inter rater reliability was used to check whether the codes, sub categories and categories drawn from the data 'made sense' to someone else. This was addressed by requesting an independent rater to match quotes to a list of codes for one category. Percentage agreement overall was then calculated.

### **3: RESULTS AND ANALYSIS**

#### **3.1 Overview – Emergence of the Theoretical model**

This study explored the process of recovery from psychosis, and led to the development of a temporal stage model of the process of adjustment to the initial experiences of psychosis, and diagnosis of schizophrenia.

In this chapter the results for each stage of adjustment are presented starting with an explanatory diagram and an overview for that stage. Each stage represents the central category generated from selective coding, and is presented with the categories, subcategories and codes for each stage. To aid the reader the central categories are presented in bold uppercase text, and the categories are presented in bold lower case text. The codes contained within each category are presented in quotation marks, and some categories contained subcategories and these are also presented in quotation marks. Intervening conditions, variables that effected the psychological and social processes involved in the particular stage of adjustment, developed through axial coding are represented by italics within the diagram and description of the stage where applicable. Examples of quotes from participants are presented in each stage to illustrate the categories or codes described in that stage. The quotes are accompanied by the participants' identifying number and either an F or M (female or male) to distinguish their gender. Editing of an extract is indicated by ellipses (e.g. ...). The results of the tests of rigor are then presented.

Initial analysis of the data produced 1803 codes. Open and axial coding developed categories and sub categories from these codes, and these were compared and contrasted leading to the generation of a central category for the whole process, and for each stage, by selective coding.

The central category of the emerging theory was that '**A PROCESS OF PSYCHOLOGICAL AND SOCIAL ADJUSTMENT WAS CENTRAL TO RECOVERY**', and led to the development of a stage model which identified a number of psychological and social processes occurring at each stage of adjustment. In addition, selective coding was carried out within each stage of the adjustment process resulting in a central category for each stage (e.g. In the initial stage it was 'becoming different'), to which all the categories, subcategories and codes in that stage related. The psychological and social processes occurring at each stage are outlined sequentially but as with other stage models there was some movement back and forth between the stages as this process of adjustment unfolded.

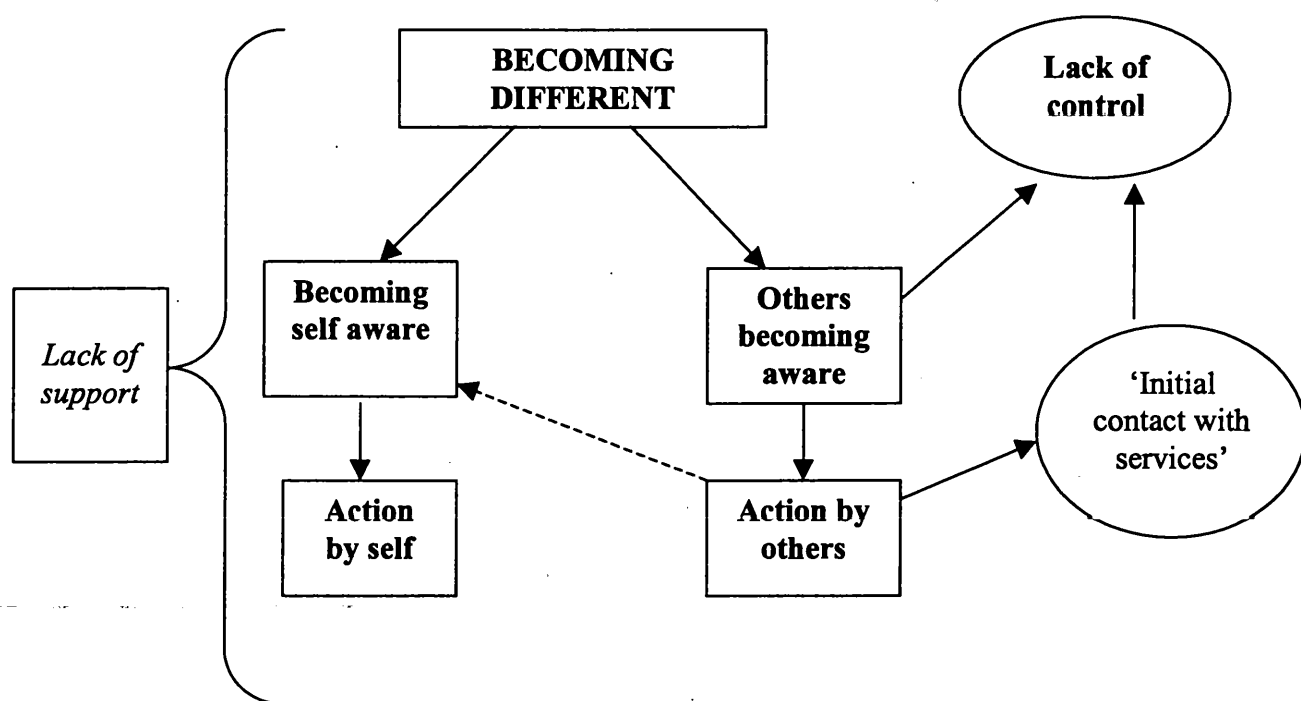
The adjustment process started prior to the diagnosis of schizophrenia, this was a stage of emerging psychosis characterised by a time when the person and the person's family noticed that they were **BECOMING DIFFERENT**. The second stage, was the time of initial contact with services and usually involved hospital admission, and receiving a diagnosis and was characterised by the **INITIAL REACTIONS** of individuals to their experiences. This was followed by the third adjustment stage, where participants were **BEGINNING RECOVERY**, and were over the most acute experiences of psychosis, and were preparing to or, leaving hospital. This led to a fourth adjustment phase, which involved a more active process of **COMING TO TERMS** with the experiences of psychosis, and diagnosis of schizophrenia. The final adjustment stage identified a longer term phase of **ACCEPTANCE AND LIFESTYLE CHOICE**.

## 3.2 Process of Adjustment

### 3.2.1 First stage of Adjustment – BECOMING DIFFERENT

This stage involved the period when the experiences and symptoms of psychosis were emerging prior to receiving input from mental health services (Figure 1).

Figure 1: Diagram depicting the first stage of adjustment – ‘Becoming Different’



During this stage the individual was **BECOMING DIFFERENT**, and was gradually **becoming self aware** along with **others becoming aware** which impacted on self awareness of difference (see Figure 1). Self awareness led to **action by self**, and awareness of others led to **action by others**, and they were often responsible for 'initial contact with services'. As illustrated in Figure 1 'initial contact with services' and **others becoming aware** led to an increasing feeling of **lack of control** by participants, and participants reported a general '*lack of support*' at this time.

The central category of **BECOMING DIFFERENT** was developed from the categories and codes described.

### 3.2.1.1 Becoming self aware

The category of **becoming self aware** consisted of two codes. A 'limited awareness' of what was happening described by six participants;

*'Like I say, I can never define it and there fore I never knew it at the time' (M3)*

One participant talked about this 'limited awareness' as having a detrimental effect;

*'I think that's what my problem was. I didn't recognise it.' (M1)*

This 'limited awareness' was reflected in 'beliefs' about what was happening for five participants;

*'Cos in my head I thought it was normal type of thing. I thought people was talking to me.' (M6)*

### 3.2.1.2 Action by self

Lack of self awareness led to 'difficulty with seeking outside help';

*'Well, I didn't tell anyone I heard voices..' (M5)*

**Action by self** mainly consisted of attempts at 'self help':

*'I kept trying to get myself better.' (F8)*

### 3.2.1.3 Others Becoming aware

The category of **others becoming aware** was made up of three codes of the different people who did become aware of the participant's difference. These were 'friends', 'family' and 'wider systems', for example;

*'Well I didn't tell anyone I heard voices but I think everyone knew that I was getting ill like my friends and everyone around me because I started acting different, acting different, not being myself.' (M5)*

#### 3.2.1.4 Action by Others

This awareness by others led to the category of **action by others**. This included two codes of 'action to the person';

*'it was a lot of pressure on me. I was having bad, well my mum thought I was having bad attitude so she was giving me pressure about college.'* (F10)

*'I lost my job cos they said you know you're not fit to work here.'* (M4)

and/or 'seeking help' often from mental health services:

*' My family, my family decided that I should see a psychiatrist.'* (M3)

#### 3.2.1.5 Lack of Control

This stage was characterised by a sense of not being in control that continued into the other stages. Three participants talked about a **lack of control** at this time;

*'you know you need help but you have to wait, that's the worse thing. Well I was at that age where I couldn't phone my doctor and say doctor I'm ill I had to wait on my mum and dad. For them to notice me, that I was ill.'* (10)

#### 3.2.1.6 Intervening Conditions

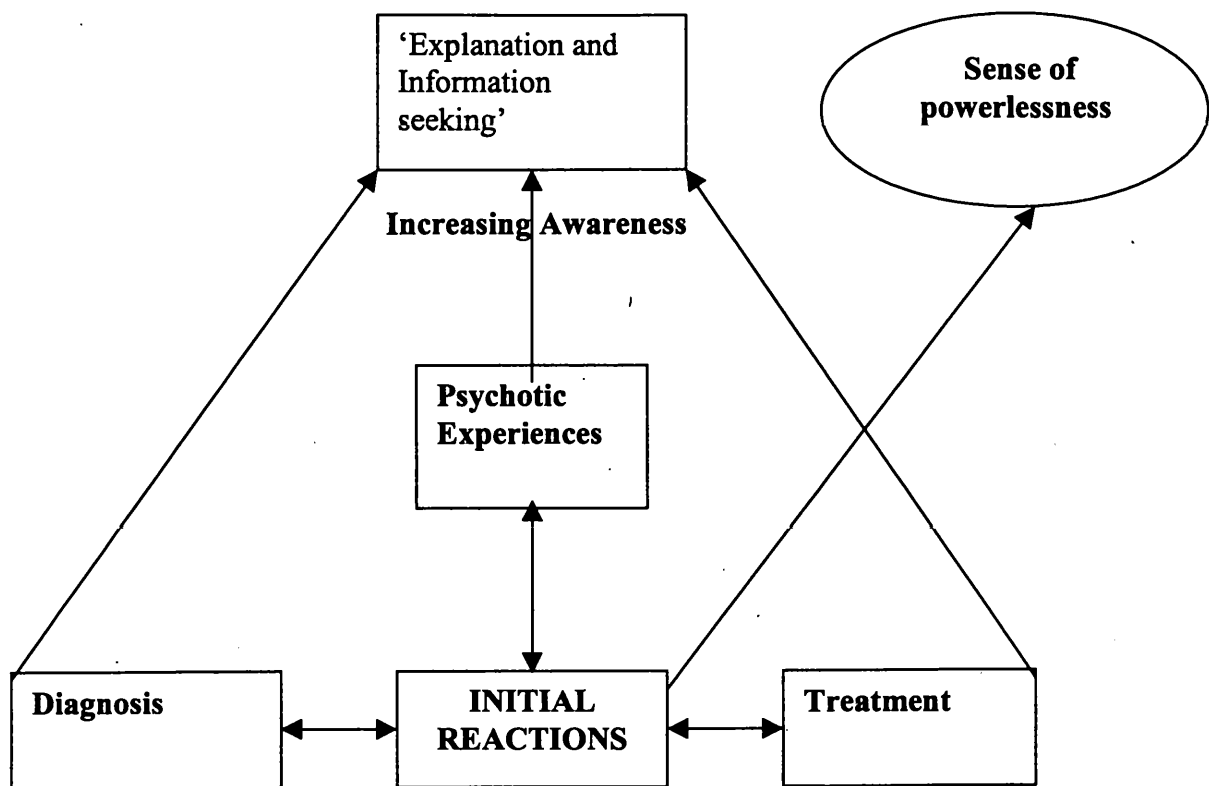
Although participants did not describe actively seeking help from services, four participants commented on a general *lack of support* at this time both by services, and social support;

*'I mean that's all that was the effect cos for ten years I was going on with all this sort of paranoia and mental health stuff and like not getting any help, taking you know more stuff and that's why inevitably you know I had psychosis.'* (M4)

### **3.2.2 Second Stage of adjustment – INITIAL REACTIONS**

The second stage of the process of adjustment involved **INITIAL REACTIONS** at the time of initial contact with mental health services, which included hospital admission and/or diagnosis giving ( Figure 2).

Figure 2: Diagram depicting the second stage of adjustment – ‘Initial Reactions’



This stage of the process of adjustment was dominated by **INITIAL REACTIONS** to the **diagnosis**, the **treatment**, and the **psychotic experiences**. There was an **increasing awareness** for women of difficulties at this time that led to a more active process of ‘**explanation and information seeking**’. For many individuals the experiences at this stage led to an increasing lack of control, culminating in a **sense of powerlessness**.

### 3.2.2.1 Reaction to diagnosis

This was the stage when people received some sort of **diagnosis** or explanation of the difference. One man when describing being told he had schizophrenia said;

*‘..cos all they said, cos I asked them what they meant. They said its something to do with the, how can I say, split personality type thing. No he didn’t say split personality, what did he say, I don’t know, I can’t remember, something about chemical imbalance in my brain and that I’d hear voices.’ (M6)*

The three main codes included in this category were:



i. Shock

Two participants talked about 'shock';

*'...When he told me I was schizophrenic it was such a shock , and I haven't got over that shock.' (F11)*

ii. Lack of understanding

Six participants talked of a 'lack of understanding' which included not understanding the diagnosis itself, or reasons for the diagnosis;

*'I didn't have a clue.' (M5)*

iii. Disbelief or Denial

Five participants talked about 'disbelief or denial';

*' All I know is they came and said I was sick and I didn't feel sick. ' (M6)*

### **3.2.2.2 Reaction to treatment**

The reaction to **treatment** by mental health services, which in almost all cases was admission to hospital was made up of three codes:-

i. Anger

Five participants describing feeling 'anger' with others including their family, and mental health services, due to the treatment they received;

*' My boyfriend, at first I was angry with him because he got me involved with all the mental health services. ' (F8)*

ii Wish to escape

Another reaction to the treatment was a 'wish to escape' talked about by three participants;

*'..so I mean I just had to shout and kick and scream to get out of there. And I did get out of there.' (M2)*

### iii. Isolation

Four participants talked of a sense of 'isolation';

*'Its like nobody cares, and nobody does.'* (M3)

#### **3.2.2.3 Reaction to psychotic experiences.**

Reaction to the **psychotic experiences** was the reaction of participants to the change in themselves at this time, the difficulties or symptoms they were experiencing. Two women's reaction to their own difficulties at this stage was by comparing themselves positively with others, 'social comparison';

*'Yeah and everyone, they put me in a mental ward. And everyone there was ill, more ill than I was.'* (F7)

The two men who described their reaction to difference described 'distress';

*'It was distressing'.* (M3)

#### **3.2.2.4 Increasing Awareness**

For four women the initial stage led to an **increasing awareness** of their difficulties (Figure 2);

*'Because enough people were telling me you know like its your thinking, its not real and all that so I was thinking maybe it is.'* (F9)

This increasing awareness led to the subcategory of 'information and explanation seeking'.

#### **3.2.2.5 Information and explanation seeking**

The subcategory of 'explanation and information seeking' comprised three codes. Three women talked of the 'limited explanations' of their experiences that they received from services, and the lack of information on whether they were 'getting better';

*'I was only given an explanation when I first came in here and then afterwards no one else would ever explain to me what was happening. You know they used to talk about my life and how I was going. But they wouldn't exactly explain what was happening to me.'* (F7)

And the 'limits of the medical model' on communication at this stage was outlined by five participants including men;

*'Cos I'd been hearing a voice or voices they said are you schizophrenic, they didn't really listen to what I was saying, they didn't take it on.'* (M2)

### 3.2.2.6 Sense of powerlessness

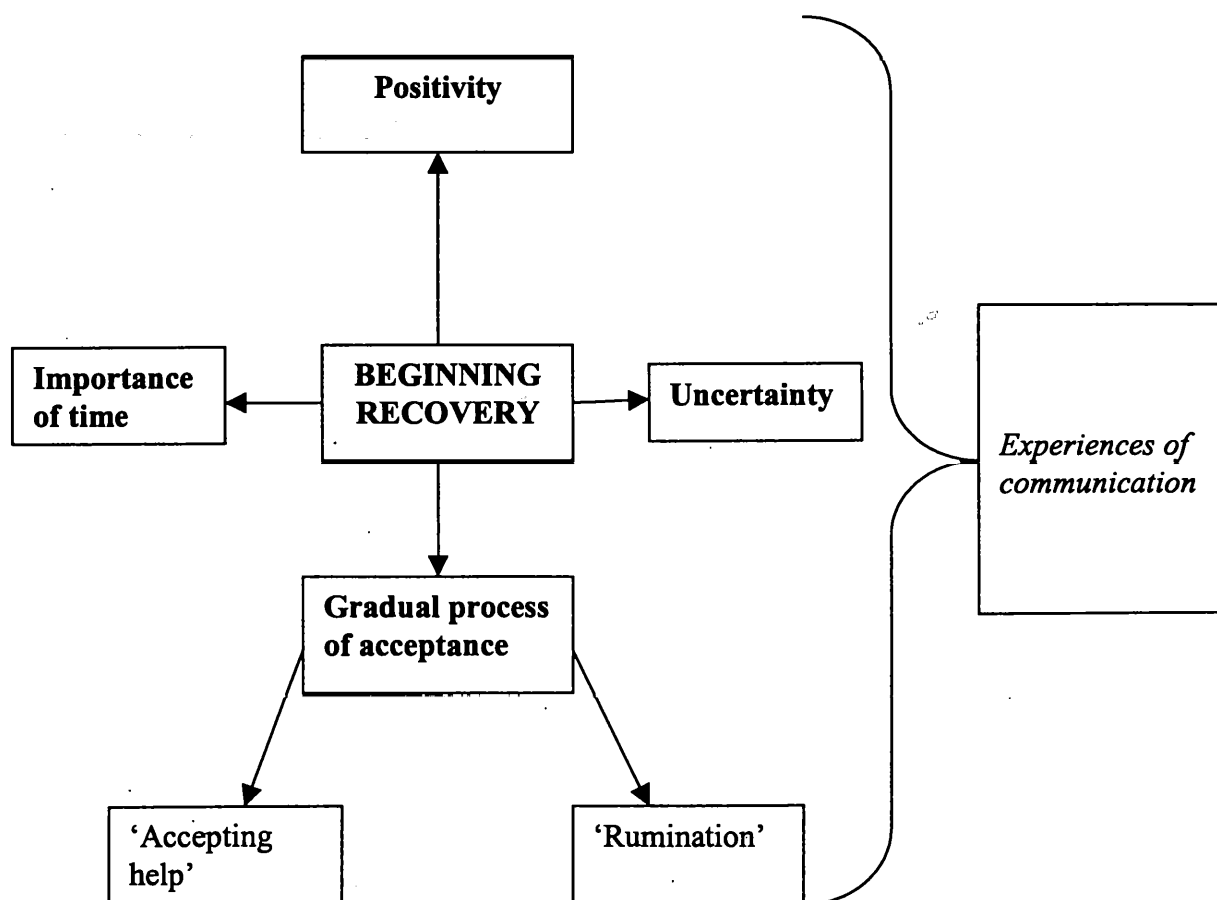
The feeling of a lack of control continued to increase in this stage, leading to a **sense of powerlessness**, talked about by three participants;

*'I felt really helpless, I felt really helpless you know, totally overpowered...'* (F9)

### 3.2.3 Third stage of Adjustment – 'BEGINNING RECOVERY'

The third adjustment stage illustrated in Figure 3, was the period of early adjustment when participants were over the most acute experiences of psychosis and usually included preparing to leave hospital and the time after initial discharge.

Figure 3: Diagram depicting the third stage of adjustment – 'Beginning recovery'



This seemed to be a stage of **'BEGINNING RECOVERY'**, which involved a **gradual process of acceptance** of experiences characterised by beginning 'accepting help', but also 'rumination' about what had happened. The other categories highlighted as important in this stage by participants included the **importance of time** to recover, and feelings of **positivity** alongside an **uncertainty** about the future.

### **3.2.3.1 Gradual process of acceptance**

Beginning a **'gradual process of acceptance'** was talked about by six participants. This included a 'reduction of denial';

*'So one of the big things for me for coming to terms with it was actually finishing all the denial.'* (F9)

### **3.2.3.2 Accepting help**

Participants talked of acceptance beginning with 'accepting help';

*'And I just sort of got under my mum's wing sort of thing.'* (M4)

Some participants highlighted aspects that were important to them 'accepting help'. The 'importance of respect and being listened to' was highlighted by three participants as helpful;

*'...someone that would listen and cooperate and treat me as an equal to him.'* (M3)

Eight participants (four men and four women) accepted help in the form of 'talking therapies' and found this aided adjustment significantly, these were defined as counselling and group therapy;

*'What has helped adjustment? Counselling, I was able to learn even though ill'* (F8)

*'I had therapy groups that helped more than anything else.'* (M5)

### **3.2.3.3 Rumination**

Gradual acceptance was accompanied by 'rumination' on the difficulties for five participants;

*'...and those are the months of hell because you're fighting yourself.'* (M3)

*'Doesn't make you feel very good. The after effects is quite devastating... to think that you picked on someone and started arguing with them and talking to them and you were convinced that they knew what you were talking about, knew who you were and they didn't. And at that time you can remember yourself being so adamant, it hurts you know..' (F11)*

### 3.2.3.4 Positivity

Four participants talked of some 'positive feelings' at this stage;

*'I thought it would pass over, I will conquer it.' (F12)*

For two participants these 'positive feelings' were accompanied by a 'desire for independence';

*'...came out of hospital. I mean I had to pull myself out of it. I mean its just, its been me.' (F8)*

Three women and one man highlighted the unhelpful 'effect of labelling and stigma' on their ability to feel positive;

*'Once its maintained once you are schizophrenic, you're permanently in it.' (M3)*

*'You know there was nothing I could do about it, there was no way I could get better. I just had to wait until I turned into a knife wielding crazy, which was obviously what happened.' (F9)*

### 3.2.3.5 Uncertainty

For two participants there was a sense of **uncertainty** which seemed to be related to the lack of control and sense of powerlessness described in the preceding stages;

*'...and I remember being really scared thinking OK if I'm ill, is that the only choice left to me?' (F9)*

### 3.2.3.6 Time to recover

The experiences of five participants contributed to the category of the **importance of time** to recover at this stage. Codes included in this were being 'able not to work', 'recovery from symptoms' and 'recovery from experiences';

*'...I was off for a long time. I needed to be off work as well, couldn't go straight back to work.' (M1)*

*'I don't know if I was still actually ill but I was still very much up in the clouds, wasn't as I am now.'*  
(F11)

Three women talked about how 'services were helpful' in providing time at this stage to recover, one woman talking about residential care said;

*'The thing that made the biggest difference to me was moving into residential care... Just do things you know like get up in the morning, make coffee, watch telly for a while, read a book, but in the knowledge that there was always someone there if you didn't feel right you know, if you felt unwell.'* (F9)

### 3.2.3.7 Experiences of Communication

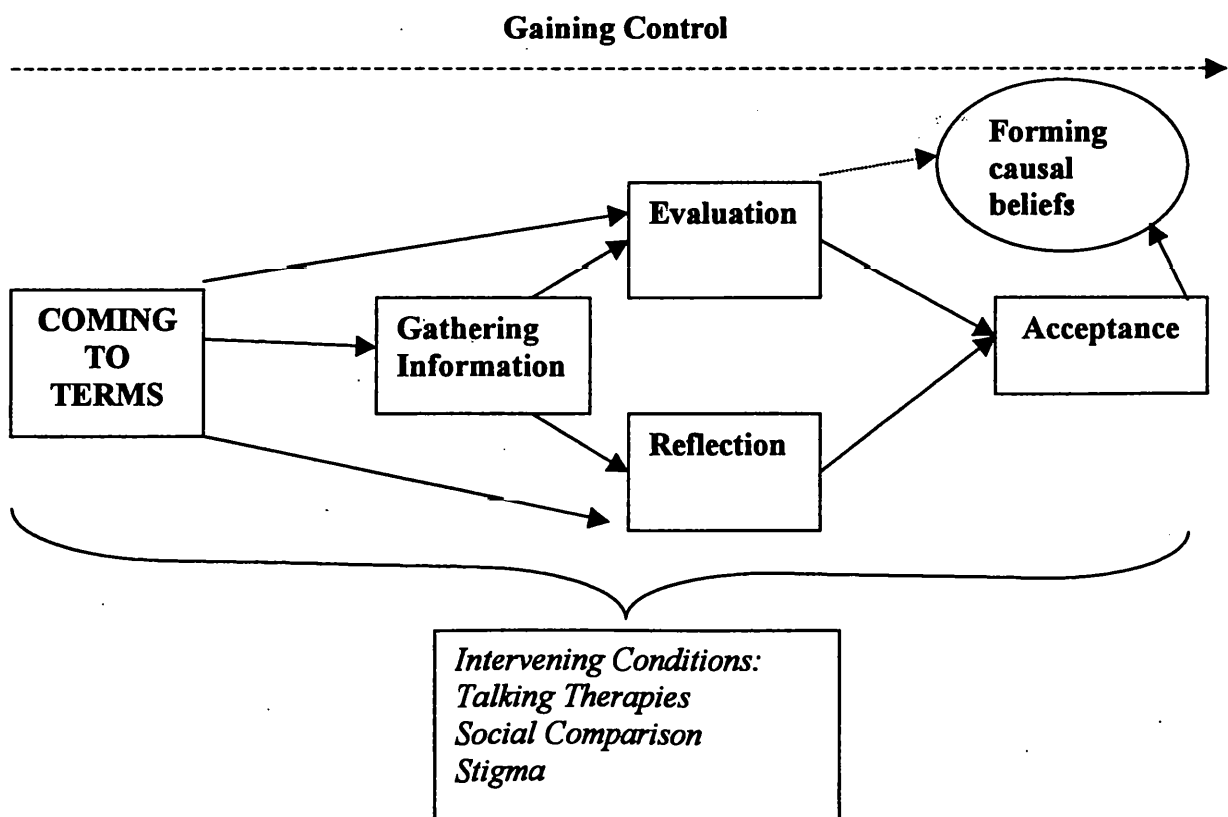
An intervening condition (see Figure 3) which impacted on the whole stage of 'Beginning Recovery' was 'experiences of communication' at this time. Seven participants highlighted this as impeding the recovery process and it was comprised of codes referring to limited information about areas such as 'progress', 'medication', and 'prognosis', for example;

*'I mean a lot of stuff like I couldn't sleep on the bed cos I was really stiff, my body was really stiff and I had to sleep on the floor and they was making ructions about it. And I thought it was there was something wrong with the bed you know and I didn't know it was cos of the medicine and I thought they should have known about that sort of thing...'* (M4)

### 3.2.4 Fourth stage of Adjustment – 'COMING TO TERMS'

The fourth adjustment stage, was an active process of 'COMING TO TERMS' with the changes that had occurred (see Figure 4).

**Figure 4: Diagram depicting the fourth stage of adjustment – 'Coming to terms'**



The process of **'COMING TO TERMS'** with the diagnosis and the related experiences included **gathering information**, and the psychological processes of **reflection** and **evaluation** about the changes that had occurred. The categories of **evaluation** and **acceptance** in this stage led to **forming causal beliefs**. As seen in Figure 4 the activity of **gathering information** also informed the psychological processes of **reflection** and **evaluation**, leading to **acceptance**. *Intervening conditions* included the role of *'talking therapies'* and for women there was a negative impact on the whole stage of comparing themselves with others, *'social comparison'*, and for both men and women *'stigma'* had a negative impact on this stage.

#### 3.2.4.1 Gathering Information

The gradual process of acceptance, started in the third adjustment stage, led to a **'COMING TO TERMS'** with what had happened, which included participants actively **gathering information**. Four participants talked of seeking 'information on diagnosis', and 'information on treatment' and cited 'sources of information' as professionals and literature;

*'No I asked, they said ask about your medication, I said look where do I find the information. They said the British National Formulary. I said I'll look into it, and I did.'* (M2)

*'I guess em...just informing self myself as much as I possibly could about my own illness you know and finding out about it you know.'* (M1)

Two women mentioned voluntary services or the user movement as helpful in gathering information;

*'I got some information from MIND, I got some information from the Hearing Voices Network and the Schizophrenia Fellowship but never from the NHS, Mental Health Services.'* (F9)

#### 3.2.4.2 Reflection

**'COMING TO TERMS'** included the psychological process of **reflection**, which was often informed by the information gathered. Five participants talked about the role of reflection at this stage;

*'well it seems like I've become more well now. And I suppose because I've become more well now and I'm on my own a lot, I think a bit more about the past.'* (F11)

*'I needed to build up a picture for what happened. Its important for me to get back to being myself.'* (M1)

### 3.2.4.3 Evaluation

Four participants talked of this being a period of **evaluation**;

*'and it makes you re-evaluate everything, it makes you realise what's important.'* (M1)

This included an 'evaluation of their own responsibility' for the experiences;

*'I mean like I'm really hard on myself, like my counsellor said and I do like blame myself for a lot of stuff you know.'* (M4)

Two participants talked of the 'role of others in evaluation' of their situation;

*'You need to hear, you need to hear what others have got to say.'* (M1)

### 3.2.4.4 Forming Causal Beliefs

The process of evaluation led, in part, to **forming causal beliefs** (Figure 4) for all participants except one, about why psychosis had occurred. For most participants more than one cause was suggested which ranged from an 'external cause', which was attributed by all men and some women;

*'Its trauma, it has to do with the past. There are a lot of unsolved mysteries in my life, people have done things to me behind my back, a lot of betrayals.'* (F12)

*'..loads of it and I was always to smoke (cannabis) that all the time and that's what really screwed my brain up, you know.'* (M6)

To an 'internal cause', attributed by one man, and three women;

*'I'm not sure. But I know I'm a worrier, cos I worry quite a lot over anything. I mean I feel that if I'm not worrying then there's something wrong that I have to worry. So it might be, so that might be the cause of it.'* (F7)

*'But now I tend to think that...I've probably had em the symptoms underlying and I was self medicating by taking drugs cos if I look back to my childhood I can see I had problems even then with things like self harm and irrational thinking right back to my childhood.'* (F9)

The forming of causal beliefs had an impact on 'attributions of control';

*'Its really for me to understand myself, the bottom line, what went wrong. And then after that, to try and stop it happening again.'* (M1)



### 3.2.4.5 Acceptance

Ten participants talked of these processes leading to an **acceptance** at this stage. This category of 'acceptance' consisted of two subcategories of:-

- i. 'Acceptance of the diagnosis' which involved deciding 'what to accept';

*'And that was their view, and I've got my own view'. (M1)*

*'Cos its like, cognitively you have to accept it. Once its finally accepted cognitively, I'm schizophrenic, theres no way of changing cognitively back to the way you were before.' (M3)*

- ii. 'Acceptance of loss' for seven participants (four women and three men), this sub category comprised of codes for 'relationships', 'future plans', and 'abilities', for example;

*'I wanted to settle down, get married and everything and because of that breakdown it didn't happen.' (F8)*

*'I had these dogs which I really loved...But people told me that I, but I can't remember, that I neglected them...I did love them a lot but Social Services took them away, I've been trying to see if I can get some of them back.' (F11)*

### 3.2.4.6 Intervening Conditions

There were three conceptual categories generated which impacted on the whole process of **'COMING TO TERMS'** (Figure 4).

- i. Three participants highlighted the importance of *'talking therapies'* at this stage. One participant when talking about counselling said;

*'..Got a lot of things into perspective through that.' (M4)*

- ii. Evaluation and Acceptance at this stage was affected by *'social comparison'* for three women;

*'see the schizophrenic side of him which I see in other people. Also I've been up in the ward, and see people they're schizophrenic, poor things like they talk to, argue with someone who's not there and throw punches – go away you evil git, you know theres not any one there. But because I don't have anything like that its difficult you know.' (F11)*

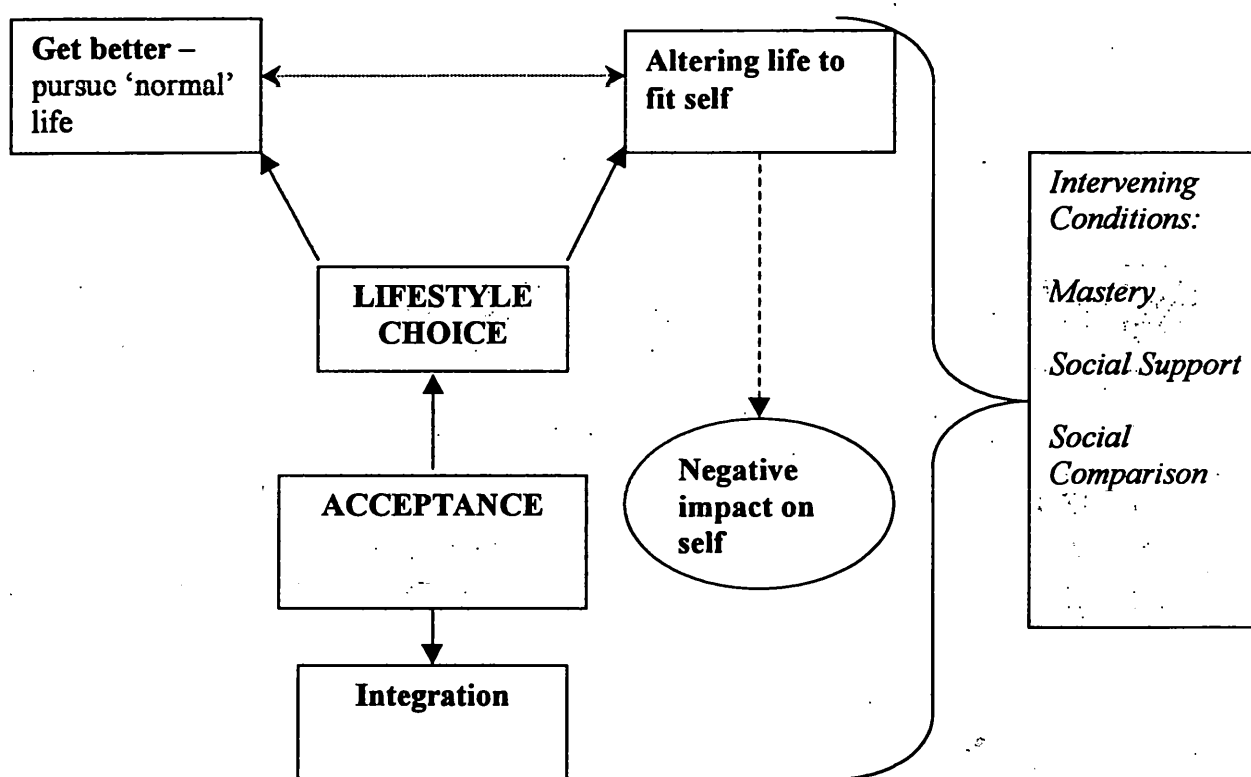
- iii. The *'stigma'* surrounding mental illness made the diagnosis more difficult to accept for five participants;

*'It's a stigma, that's the problem with mental health.' (F12)*

### 3.2.5 Fifth stage of adjustment – ACCEPTANCE AND LIFESTYLE CHOICE

After participants had come to terms with some of their experiences, the fifth stage of adjustment seemed to start with 'ACCEPTANCE' that had occurred in the last stage and the making of a 'LIFESTYLE CHOICE' which depended on the form of acceptance (i.e. What had been accepted) (see Figure 5).

Figure 5: Diagram depicting the last adjustment stage of Acceptance and lifestyle choice.



ACCEPTANCE led either to a LIFESTYLE CHOICE to get better, pursue a 'normal' life, or an altering life to fit self. As shown in Figure 5 there is movement between these two states. For some participants who altered life to fit self this led to a negative impact on self. ACCEPTANCE at this stage also led to an integration of the person's experiences with their sense of self, which allowed acknowledgement of both positive and negative aspects of

experiences. *Intervening conditions* that impacted on the whole stage were a sense of *mastery*, importance of '*social support*' was highlighted again and '*social comparison*' by women.

### **3.2.5.1 Get better - pursue a normal life.**

Four men and two women described their goal as **getting better** and way of living as pursuing a 'normal' life.. This category included a 'rebuilding of identity' outside of mental health services;

*'I want to see less of people in the psychiatric system, more of people outside'. (M2)*

This was associated with 'attributions of control', the belief that it would not happen again;

*'And it was just like one period in time but now it wouldn't ever happen again.' (F10)*

### **3.2.5.2 Altering life to fit self**

Ten participants talked about making changes in their lives to accommodate their difficulties. This category included a code of 'acceptance of a long term vulnerability' and they highlighted the effects of this on areas such as ability to work, where they lived and who with, and relationships. Four women and one man talked of the acceptance of the long term nature of schizophrenia as being part of adjustment.

*'I just have to accept that I'm ill. I'm ill, you just have to accept these things.' (F8)*

*'It's a stigma and it stays with you and its not anything that's a soft option. No you find it very hard to get back into work with it and everything you know.' (F11)*

For six participants '**altering life to fit self**' included the subcategory of '**managing illness**';

*'I said to myself I won't allow this to happen again. So when I came back I found that I wasn't sleeping. So 2 weeks I did not sleep, I said this thing has come back. So I went to my doctor, I said give me a sleeping pill, he did.' (F12)*

The participants who talked of '**managing illness**' spoke of internal variables that were helpful, '**self help**';

*'Plus this time, I'm tougher mentally, I'm mentally tough.' (M5)*

And external variables, the 'use of services'. One participant talked of requesting admission;

*'and they let me in...they let me in for a few days.' (M4)*

### 3.2.5.3. Negative impact on self

This particular choice of 'acceptance of a long-term vulnerability' was associated with feelings of 'anxiety' and 'depression' for five participants;

*'Feels scary to think it could happen again.' (M4)*

*'It was just a few weeks ago when I was feeling I wasn't getting anywhere in life. I was always going to feel ill.' (F7)*

Accepting a diagnosis of schizophrenia had a mainly 'negative impact on self-image' for six participants;

*'Because as an adult you're supposed to be independent, self sufficient, self-reliant. So you can't cope, you can't manage, you can't take care of yourself, you can't take care of your daughter, is it that bad? You've lost it.' (F12)*

For two women this was related to 'cultural acceptance';

*'Well you see I was still depressed because within my community, African community I can not be accepted, because they keep saying you're still unwell, you don't do nothing, you're lazy.' (F12)*

*'Well that, that probably made my depression worse because I thought that because it was something...shameful that maybe I had something bad.' (F7)*

### 3.2.5.4 Integration

The final stage of **ACCEPTANCE AND LIFESTYLE CHOICE** also involved integration of the positive and negative aspects of the experience for seven participants(Figure 5):-

This included the 'impact on self';

*'It has tainted my life. But at the same time it has brought me blessings.' (F12)*

Three men talked about the 'impact of the symptoms' on themselves, and this was mainly negative;

*I: Were there any negative changes in your self?*

*P: Like I say, a bit of a dull mind, not such a spark.' (M4)*

But two women acknowledged some positive impact on self of the symptoms;

*'Now things that I used to find easy, I now find really difficult...its made me a more diligent person, its taught me perseverance. They're things that are hard...and er I persevere more now with things like that than I used to.'* (F9)

There was also an 'impact on relationships' highlighted;

*'That's something you learn, who was there, you're there for them.'* (M1)

### **3.2.5.5 Intervening conditions**

Three participants talked of the role of a sense of '*mastery*' in recovery at this stage, both in acceptance of a long term vulnerability and in helping the negative impact of that;

*'So that was the year of 1996, a year of achievement. When people ask me what are you doing, I'm in college. You boosted my ego.'* (F12)

Six participants talked also of the continuation of the important role of '*social support*';

*'My family, especially my mother are very aware of my illness'* (F8)

*'Actually if I had people who understand me and support me. I really wouldn't be on medication now. I would have recovered.'* (F10)

Three women talked of the effects of comparing themselves with others, '*social comparison*' at this stage;

*'Well, at the moment I haven't really got much going for me except for my job. I mean, when I look around I think of the people that have got lots of things going in their life like all the excitement they have in their life. And I look at my life and I think, God nothing like that'* (F7)

## **3.3 Tests of Rigour**

### **3.3.1 Inter rater reliability**

An independent rater was given a summary of the codes for the second stage of adjustment, '**INITIAL REACTIONS**', (Appendix 7), and a separate list of the quotes that led to the codes. They were asked to match the quotes to the codes. This generated a percentage agreement of 88%.

### **3.3.2 Respondent validity**

A summary of the stage model of adjustment was sent to two participants, who had consented to give written feedback. However, they did not provide any feedback, and therefore respondent validity could not be assessed.

## **4: DISCUSSION**

The discussion is divided into six sections. An overview of the results which includes a diagram illustrating the proposed stage model of adjustment (Figure 6), is followed by a discussion of the main findings under the heading of each research question. The third section is a discussion of tentative findings that emerged from the data which were not covered by the research questions. The limitations of the research are then considered. Finally, the implications of the results for clinical practice, and future research are discussed.

### **4.1 Overview – A Theoretical Model of the Process of Adjustment to the experiences of psychosis and a diagnosis of schizophrenia**

The data generated from the interviews led to the development of a temporal stage model of the process of adjustment to the experiences of psychosis and a diagnosis of schizophrenia (Figure 6). The experiences and diagnosis affected participants in a number of different ways, the effects were intrapersonal (e.g. loss, lowered self esteem), and interpersonal (e.g. relationships, occupation). The impact of the disorder started in the stage of emerging psychosis, the initial stage of **BECOMING DIFFERENT**, when there was often limited self awareness of any difficulties, but others surrounding them became aware and gradually took action. The second stage of adjustment was likely to involve hospital admission, and was characterised by **INITIAL REACTIONS** to what had occurred accompanied by a growing sense of awareness for women. The third adjustment stage or **BEGINNING RECOVERY** was the period surrounding hospital discharge, which constituted the start of recovery as participants 'recovered' from the psychosis, but also the consequences of the psychosis, such as, hospitalisation and changes in role, and participants were more able to accept help. The fourth phase of adjustment was at a stage when participants felt able to be more active in the process of recovery or **COMING TO TERMS** with their experience. This included evaluation and

reflection on what had occurred, which led to increasing acceptance. This **ACCEPTANCE** led to a **LIFESTYLE CHOICE** which constituted the final stage of adjustment where individuals made choices about how to live their lives based on their experiences and the attributions made in the preceding stages.

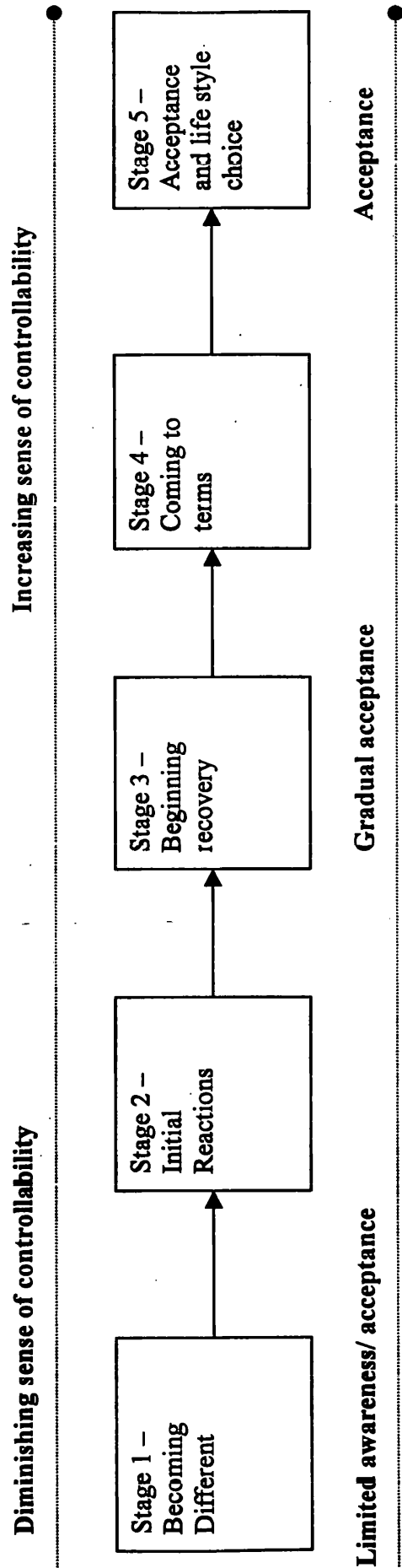
The psychological processes were outlined at each stage, along with intervening conditions that appeared to have an impact on these psychological processes (Figure 6). Throughout the process of adjustment, two main themes arose:-

- **Acceptance.** The process of adjustment involved participants embarking on a gradual process of acceptance.
- **Control.** Attributions of controllability also continued in a changing format throughout the process of adjustment.

Figure 6 illustrates the process of adjustment to the experiences of psychosis, and a diagnosis of schizophrenia.



**Figure 6: Diagram depicting a stage model of the process of adjustment to the experiences of psychosis and a diagnosis of schizophrenia**



**JOANNA SELLER BSc Hons**

VOLUME 2

**A STUDY EXPLORING THE PROCESS OF ADJUSTMENT TO  
THE EXPERIENCES OF PSYCHOSIS AND A DIAGNOSIS OF  
SCHIZOPHRENIA.**

A thesis submitted in partial fulfilment of the requirements of the Open University for the  
degree of Doctor of Clinical Psychology

**NOVEMBER 2000**

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## **4.2 Research Questions**

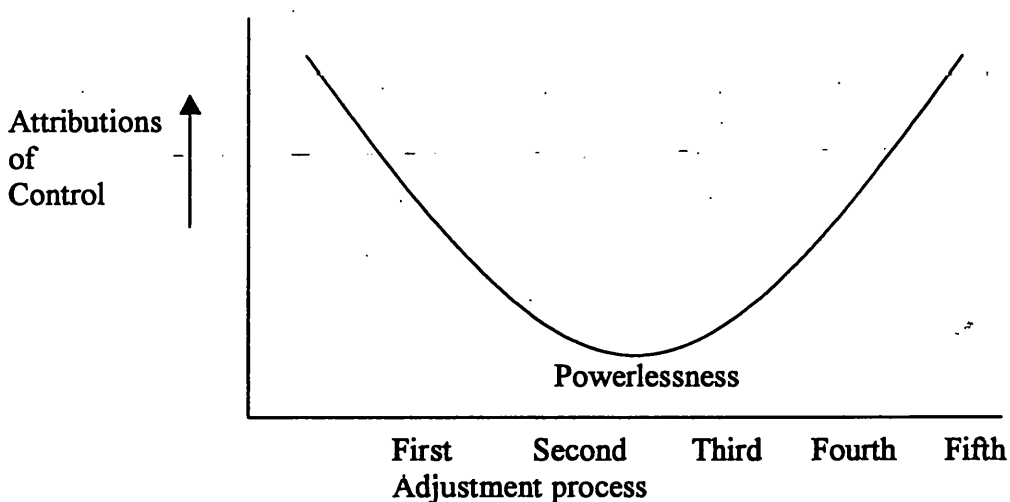
### **4.2.1 What is involved in the process of adjustment?**

This section will discuss the main findings presented in the results in relation to the salient issues and themes that arose throughout the whole process of adjustment. The main themes that arose will be discussed with regard to their impact at each stage of adjustment.

#### **4.2.1.1 Control**

One area that was particularly salient at all stages of adjustment was control. This was in line with Taylor's (1983) model of adjustment describing the importance of attributions of control to adjustment. Figure 7 illustrated the process of making attributions of control.

**Figure 7: Diagram depicting attributions of control over the whole adjustment process.**



As shown in Figure 7 in the first stage of adjustment there appeared to be an increasing lack of control over management of the symptoms, and the impact of these symptoms on the individual's life. This seemed to be accompanied by a 'taking control' of the situation by others as they became increasingly aware of differences in the person, and took action, which decreased the individual's sense of control. For most participants this culminated with an

admission into hospital generally organised by others and was sometimes compulsory. This seemed to have the effect of further diminishing participants' sense of control. These two stages comprised the components of what is termed a 'depressogenic' situation by Rooke and Birchwood (1998):

- Loss – A fixed subordinate role, a loss of their previous role and being placed into a role where others were making decisions for them.
- Humiliation – Events which undermine the person.
- Entrapment – A punishing situation with a disbelief in own abilities.

In the first stage participants had often lost their job or place at college, and especially for younger participants there was increased reliance on their parents at this time. These experiences seemed to be consistent with the components of loss and humiliation described above. Admission into hospital, generally based on the decisions of others, and the experiences they had in hospital such as sedation would again be consistent with the component of humiliation but also of entrapment especially if the admission and medication taking was compulsory by a legal section.

Rooke and Birchwood (1998) found that these factors formed a 'depressogenic' situation, in essence, they were associated with the co-morbidity of depression in people with psychosis. The present study suggested that this situation led initially to a feeling of powerlessness which was further reinforced by being given a diagnosis which was perceived as unchangeable. For some participants this sense of powerlessness continued into the third adjustment stage leading to continuing uncertainty about the future and their own abilities to cope and adjust. This uncertainty has been found in physical illnesses (e.g. Wiener, 1975) to be one of the major stressors associated with a chronic illness.

In the fourth stage of adjustment participants began to regain control by gathering information and forming their own opinions. This had started earlier in some cases for female participants as they sought information from professionals while in hospital. In the fourth stage of adjustment, evaluation of information and their experiences, led to forming causal attributions.

Making causal attributions has been discussed in great depth by researchers such as Sensky (1997) again in relation to physical illnesses. He suggested that they started to occur when the person is initially faced with the illness, perhaps in the earlier stages when individuals with physical illnesses are endeavouring to make sense of their symptoms. However, in this study the making of causal attributions seemed to occur later in the process, in the fourth adjustment stage, when participants could begin to come to terms with their experiences.

In these participants the causal attributions fitted well with their belief about the controllability of their disorder. For example, a few participants felt that psychosis was the result of taking drugs, and therefore that taking drugs in the future could lead to relapse. The present study did not find the 'accuracy' of causal attributions to be important. This maybe because the cause of psychotic experiences is still unknown (Lavender, 2000) and therefore the 'accuracy' of causal attributions is difficult to establish. What seemed to be important was the validity of the attributions to the individual, in essence, how much they made sense to the person and how they helped them to manage their difficulties.

These causal attributions were a part of participants' forming a 'narrative' (White, 1987) about their experiences, in most cases this assisted their sense of control, and led to a choice of how to live their lives in the last adjustment stage. This study supported findings from studies such as Rooke and Birchwood (1998), and Birchwood et al. (1993) that found depression to be associated with lower perceived control over the illness. For participants who had accepted a

long term vulnerability to psychosis, concerns about relapse and their control over that, appeared to lead to feelings associated with depression such as hopelessness, and a negative self image. Participants who did not accept this vulnerability, and believed the psychosis would not reoccur, did not express these feelings associated with depression. These findings provided further support for Birchwood et al. (1993) who found co-morbidity of depression in psychosis to be related to acceptance of a long term vulnerability.

#### **4.2.1.2 Acceptance**

Acceptance was another theme, related to controllability that was part of the discourse on adjustment. The term acceptance is used here to signify a recognition and awareness, of their experiences by participants, and of the impact of those experiences on themselves. In the first stage there appeared to be no acceptance as there was a limited recognition or awareness of any difficulties by the individual. This continued into the second stage of adjustment where the increasing lack of control discussed previously, and psychological reactions to the situation, such as denial, seemed to preclude acceptance.

This lack of acceptance is often referred to in mental health services as a lack of insight. However, 'insight' has been defined by David (1990) as encompassing three dimensions: awareness of illness, the capacity to label psychotic experiences as abnormal, and treatment compliance. Acceptance maybe an aspect of all of these but the validity of the concept of insight itself is being increasingly questioned by researchers such as Beck-Sander (1998), and Perkins and Moodley (1993). Lack of insight is often seen as a consequence or even a symptom of psychosis, illustrated by this quote from David (1990): "Expecting any insight from a psychiatrically ill person is asking for a great deal, but not the impossible." (p.799). An initial lack of acceptance of various aspects, such as diagnosis, explanations, or treatment, at an early stage of adjustment seemed to have been for these participants a 'normal' response in the

initial stages to a serious life event. This suggests support for the theoretical model of Appelo et al. (1993) when they compared adjustment in schizophrenia to the grief process, where initial shock and denial are experienced before a process of acceptance is embarked upon.

Acceptance seemed to begin with an acceptance of help and support by others. This acceptance of help contributed partly to a stabilisation of the psychotic episode and allowed the processes of evaluation and reflection in the fourth stage of adjustment to begin. This building of a narrative about experiences of psychosis seemed to allow participants to make a choice about what to accept, and then how to adjust their life style in the final stage.

Acceptance in the last two stages included the making of causal attributions discussed earlier, which for some participants included acceptance of responsibility. It also included accepting the impact on future life, which involved either accepting a 'label' of schizophrenia, or not accepting the label or a long term vulnerability to psychosis, and pursuing 'normal' life. When the diagnosis of schizophrenia was accepted, it appeared to lead sometimes to a negative impact on self associated with feelings of anxiety, depression, and a negative self image. This was consistent with the findings of Warner, Taylor, Powers and Hyman (1989) who found that acceptance of a diagnostic label of mental illness was associated with low self esteem. This would seem to affect the enhancement of self esteem outlined by Taylor (1983) as a factor in the process of adjustment. Warner et al also found low self esteem related to acceptance of the label, to be correlated with the perception of stigma associated with the mental illness.

The impact of the stigma of a diagnosis of schizophrenia will be discussed later, but the stereotypes attributed to schizophrenia appeared to play a crucial role in acceptance of the diagnosis. The two main stereotypes described in relation to acceptance of the diagnosis were: the negative connotations of behaviour associated with the disorder (e.g. violence), and the

widely held perception of schizophrenia, as a chronic, disabling condition. The findings from this study supported previous research by Birchwood et al. (1993) which found acceptance of the cultural stereotypes of mental illness to be associated with depression.

#### **4.2.1.3 Time**

The stage model developed was a temporal model. Time was highlighted as an important part of the adjustment process. The adjustment process occurred over a long period of time, although the length of each phase varied between individuals. Time was particularly required in the third adjustment phase of beginning recovery when people discussed often still being 'unwell'. The notion of a variable, and often long recovery period seemed to support the link between the process of adjustment described here and the grief model (Wortman and Silver, 1989) which assumes the grief process to be lengthy, and variable.

The issue of time does not seem to have been covered substantially in the cognitive models of adjustment to schizophrenia (e.g. McGlashan, 1987). The choice of lifestyle that seemed to be made in the final adjustment stage, shared many aspects with McGlashan's recovery styles outlined in the introduction. The acceptance of a long term vulnerability and efforts to manage the illness, was similar to the 'integrated recovery' style. The pursuing of a 'normal' life had similarities with the 'sealing over' recovery style, such as the isolation of the psychotic episode from the rest of life. However, McGlashan, Levy, William, and Carpenter (1975), and McGlashan (1987) seem to suggest that these recovery styles can be used to describe the whole recovery process. This research found that although aspects of them influenced the process, such as the ability to take responsibility, other stages, such as coming to terms with the experiences, had to be gone through before a particular recovery style may be adopted.



## **4.2.2 How does the psychosocial impact of a diagnosis of schizophrenia relate to the process of adjustment?**

### **4.2.2.1 Stigma**

This has been discussed briefly in relation to acceptance of a diagnosis of schizophrenia. The diagnosis of schizophrenia affected how participants viewed themselves. Participants' own understanding of the meaning of schizophrenia, such as involving violence and bizarre behaviour, seemed to lead to a negative impact on their self image. This view appeared to be substantially influenced by the media coverage and lay views of schizophrenia, supporting the findings of the recent MIND survey (Baker and Macpherson, 2000).

Another related aspect of the diagnosis which was distressing to participants was its longstanding nature, and the lack of potential for change. The stereotype of schizophrenia as being a chronic, disabling condition was highlighted in relation to feelings of anxiety associated with relapse, and feelings of hopelessness about the future resulting in depression. Although, increasingly the body of research on the recovery movement is showing a much more hopeful picture (e.g. Harding et al., 1987), this information did not seem to be translated into practice in mental health services, or the beliefs of participants.

The stigma of the label also affected relationships substantially, and this was related to culture in the experience of women. For participants who's culture believed that mental illness was 'shameful', the impact was a withdrawing of support from family and friends just at the time when it was needed most.

#### **4.2.2.2 Social Comparison**

Taylor (1983) highlighted the rebuilding of self esteem as a main factor of adjustment, and outlined the importance to this of social comparison processes, i.e. comparing self favourably with others. In the present study women often compared themselves with others, however this was generally not a self-esteem enhancing process. The impact of stigma discussed above hindered this process. Women seemed able to make favourable social comparisons with other mental health users (e.g. on level of illness), and able to draw on inspiration from achievements of others, such as reading about other user's experiences and coping strategies. However, comparing themselves with others in wider society, family and friends, generally resulted in feelings of depression and hopelessness. For women it seemed to represent their perceived loss of a 'normal' life. Men did not discuss comparing themselves in relation to others, and did not seem to experience the same hopelessness as women.

#### **4.2.3 What aids or impedes this process of adjustment?**

Although the psychosocial impact of a diagnosis of schizophrenia tended to impede the process of adjustment, there were other areas that were consistently mentioned as supporting or hindering that process. It was interesting that in the first and second stages participants found it difficult to highlight what was helpful, except feeling if they had more support the adverse experiences of psychosis may have been prevented. This was also a time when help was very difficult to accept.

##### **4.2.3.1 Support and Understanding**

Support and understanding from others, both in services and wider systems, was consistently highlighted as important to the process of adjustment especially in the later stages. This was defined as both practical support (e.g. suitable accommodation) and emotional support through

empathy and understanding of others, and for some participants this was accessed through the user movement. However, support and understanding were often limited for a variety of reasons, such as cultural rejection of the participant from their community, or available resources from both services and family. The importance of having contact with people with similar experiences, probably due to the implicit shared understanding, was highlighted as supportive and some women had accessed this through the user movement. The men interviewed in this study, although acknowledging the supportive nature of contact with others with similar experiences, had not accessed this through the user movement. In addition to emotional support provided in some cases through understanding, practical support was also highlighted as very important especially during the early stages. This importance of support in recovery from psychosis has been highlighted by many other researchers in this area (e.g. Warner, 1994).

#### **4.2.3.2 Talking Therapies**

In line with research coming from the user movement (e.g. Orrin, 1996) the talking therapies were highlighted as useful from the early adjustment stage onwards, and were one forum where support and understanding were offered. Group therapy was found to be particularly helpful earlier in the process perhaps because of the implicit understanding offered by being in the same situation. Counselling was also highlighted as being helpful especially in the last two stages of adjustment for reflection, evaluation and managing the illness.

#### **4.2.3.3 Limits of the Medical Model**

Participants in this study used the term medical model to define what they felt was the prevailing view in psychiatry, of schizophrenia as a long-term disorder, and the preferred mode of treatment as medication. Participants reported that the medical model's emphasis on external control was unhelpful, such as the value placed on medication. This supports previous

user accounts, such as Hart (1995), of this as a negative experience with participants describing a negative impact on their own perception of their level of control, and a devaluation of their experiences. Participants talked of the detrimental effect of the lack of information available on 'self help'. There was also a general feeling of not being listened to, especially when talking of the experience of 'psychiatric interviews'. They appeared to think that professionals' views, such as beliefs about the potential for change impacted on their ability to move forward and adapt. Earlier research, such as Fisher, Newton, and Sainsbury (1984) provides evidence to support this belief when they found a significant belief amongst mental health workers that no significant improvement could be achieved by working with people with severe mental disorder. However, more recent research, such as McGuire (2000), although from the USA, suggests these beliefs may be changing as professionals begin to acknowledge the concept of recovery from schizophrenia.

#### **4.2.3.4 Lack of information**

Participants described often not being given any information, or being given information at too early a stage when they were unable and perhaps unwilling to take it in. The information seemed rarely to be offered again when participants felt it would have helped, and enhanced their quality of life. An example of this lack of information is in the prescribing of medication. One participant talked of being in hospital and having a very stiff neck. He assumed this was a result of the bed aggravating an underlying back problem and to alleviate this chose to sleep on the floor rather than on his bed. Nursing staff became frustrated with this, seeing this as a behavioural symptom of ongoing psychosis. He later learned that stiffness was a side effect of his anti psychotic medication. Just this information would have made a considerable difference to his well being, and his relationship with nursing staff on the ward. The importance of sharing information has been reviewed extensively within literature on physical illness (e.g. Rogers, Pilgrim, and Lacey, 1993).

## **4.3 Tentative findings emerging from the data**

### **4.3.1 Variability in recovery**

There was a degree of variability of recovery, both within and between participants. Many participants talked of their 'adaptation' to their situation as being dependent on their mood, and events that were happening in their lives at any given time. Acceptance of what had occurred generally led to a choice between two ways of approaching life although people moved between them, and between the stages of adjustment. This links well with Anthony's (1993) description of the recovery process when he stated that recovery involves moves forward and backward.

There seemed to be a link between variability and gender. Women appeared to move through the adjustment process, especially at the early stages, faster than men. For example, they described becoming aware of their difficulties earlier than men, and accepted help and sought information earlier. This provides tentative support for research suggesting better outcomes for women on measures of social adaptation (Childers and Harding, 1990). However, these differences may also be linked to age as in this study the women interviewed were substantially older than the men. This is consistent with epidemiological research which has found age of onset to be consistently higher for women than men (Angermeyer and Kuhn, 1988). In this sample men were more likely to have experienced their first psychotic episode during adolescence. Developmental research (e.g. Erikson, 1959) has defined adolescence as a time where identity is formed, and adult beliefs and attitude systems are built. The timing of the psychotic episode for those participants in late adolescence means that rather than the adjustment process including a rebuilding of identity, it may have involved an actual construction of that adult identity with all the additional stressors accompanying a diagnosis of mental illness.

There was a certain degree of individuality. For most participants there was an integration in the last stage of adjustment of the positive and negative impact of their experiences. The attributions made about different aspects of the experience differed between individuals, in essence what one participant perceived as a negative experience, was construed positively by another. This supported researcher's, such as Chadwick (1997), assertions of the individuality of the experience, but also the importance to the process of adjustment of being able to identify strengths and resources. As has been shown this seems to be related to controllability and acceptance, but also learning how to cope with experiences which can lead to them being evaluated more positively. This finding does not correlate with Lindgren, Burke, Hainsworth and Eakes (1996) chronic sorrow model of chronic illness that suggests an increasing sadness over time.

## **4.4 Methodological Critique**

### **4.4.1 Evaluation of the Method**

The strategies outlined in the method chapter were used to evaluate the findings of this study and are discussed below: -

#### **4.4.1.1 Auditability**

A research diary (Appendix 6) was written to make the research process transparent, showing the steps in thinking and action that led to the final report. This included the researcher's own thoughts and beliefs about the subject, the emerging thinking about the model, and reflections on the research process. This process of reflexivity not only makes this explicit for others, but also encouraged recognition throughout the research process of internal influences on the research.

Details of code and category generation are included in Appendix 7, showing the central categories, sub categories and codes developed through open and axial coding. In order to demonstrate how the findings are 'grounded' in the data an example of some of the quotes that informed the generation of codes and subcategories for the category of 'others becoming aware' which forms part of the first stage of adjustment are shown in Appendix 8. In Appendix 9 there is a full transcript of an interview, and contained in Appendix 10 is an excerpt from an interview transcript with coding.

#### **4.4.1.2 Respondent Validity**

Respondent validity (Henwood and Pidgeon, 1995) aims to elicit the views of participants on the researcher's interpretations. A written summary of the emerging model was sent to two participants, a man and a woman, and their feedback was requested. However, no reply was received and therefore respondent validity could not be assessed.

#### **4.4.1.3 Inter rater reliability**

Audiotaping of the interviews ensured accurate representation of the interviews, which would be available for scrutiny by independent researchers. Inter rater reliability was used to check whether the codes and categories drawn from the data 'made sense' to someone else. An independent rater matched codes to quotes from the section on 'Initial stage of adjustment', and found a reasonably high percentage agreement rate. However, this was only for one stage of the model, and no assumptions can be formed about the reliability of the other stages from this result.

#### **4.4.2 Methodological and Conceptual issues**

##### **4.4.2.1 Recruitment of Participants**

The small sample used in this study may not be representative, and does not aim to be representative of the wider population, and this means that the results can not be generalised to a larger sample. However, the aim of this research was not to provide generalisable findings, but to generate a model representing the experiences of the participants in this sample. The issue of whether the model is generalisable is subject to further research, and whether other people, including mental health workers, and users, find it a useful explanatory framework..

Participants were recruited from mental health services, and most of the interviews were carried out at the location where the participant received services. It was therefore possible that the location, and the power imbalance inherent within mental health services may have restricted their responses (e.g. limiting criticism of service provision). Efforts were made to restrict this bias, by emphasising the independence of the researcher, and the confidentiality of responses by participants.

One of the inclusion criteria was a diagnosis of schizophrenia, and some researchers, such as Bentall (1990), have argued that samples should not be selected on this basis. However, the diagnosis of schizophrenia is used extensively within mental health services, and the present study was partly focused on adjustment to receiving that diagnosis.

##### **4.4.2.2 The Interviews**

Although participants with acute psychosis were excluded, some participants did have difficulty expressing their thoughts. This meant that some interviews were more structured than others, and it is recognised that this may have meant that some respondents had more influence from the researcher than others.



The interviews could potentially elicit material that would have a significant emotional impact on the participant (e.g. descriptions of loss). The researcher endeavoured to be conscious of the subjective effect of the subject matter on participants, and interviews were paced accordingly. It was also highlighted in the briefing procedure that participants were free to discontinue the interview at any time, and debriefing after the interview was an important part of the process. The time constraints for the study meant that interviews were conducted over a single encounter and therefore the amount of trust and safety in the relationship was limited which may have limited personal disclosure.

#### **4.4.2.3 Analysis**

Analysis using grounded theory arises from a phenomenological perspective that assumes a relationship between what a person says, and the psychological constructs that they hold. This rests on assumptions that participants are able to express how they feel, and are willing to express this to the researcher (Hollway and Jefferson, 2000). The Grounded Theory analysis of 'what was said' may not actually reflect the inner world of the participant, and does not easily take into account psychological processes, such as defence mechanisms, which impact on what is said.

A central tenet of Grounded Theory is the parallel process of data collection, and analysis (Strauss and Corbin, 1998). There was some parallel data collection and analysis but thoughts and ideas arising from the emerging model, although they could be tentatively applied to the data, could not then be applied to the data collection to enhance the emerging model. Respondent validation may also have enhanced emerging theory, and the lack of response was regrettable. It is recognised that consent could have been sought to meet with participants personally to get feedback, and this may have increased the response rate.

## **4.5 Clinical Implications**

The complex processes involved in adjustment seem to require an integration of services, and suggest clinical implications for all levels of service: medical, social and psychological.

### **4.5.1 Medical Implications**

The diagnosis of schizophrenia has a significant impact and appeared to lead to an increasing sense of lack of control, and an integral part of adjusting to this diagnosis seemed to be a gaining back of control. This process could be facilitated by services at a number of stages and levels. For example, participants described feeling disempowered through the lack of information that was available to them, and the way information was given. Information regarding diagnosis and treatment appeared important in the recovery process. There has been much interest in the physical health literature concerned with sharing information and 'breaking bad news' (e.g. Buckman, 1992). For example guidelines on giving diagnoses emphasises the importance of assessment of how much the person can take in, or wants to know, and breaking down information into small manageable chunks (Brewin, 1991).

A way of facilitating clients' own control and responsibility for their illness may be through the choice of anti psychotic medication. There is now a wide choice of anti-psychotic medication (Hawkins, 1999) and part of the decision of which one to prescribe could include discussion with the client to enable them to be included in an informed decision. When clients are able to have some impact on the decision this should be encouraged rather than denied. Medication was talked about, by participants in this study, in relation to their sense of control over the whole process of recovery. This choice making regarding medication could be incorporated within care plans. For example, Perkins and Repper (1996) suggest that while a person is well enough, a crisis plan is agreed with them including plans or medication in the event of a

relapse. Involving clients in the prescribing of maintenance medication, for example in decisions of dosage and when to review, would assist them in gaining control and accepting responsibility, the crucial areas of adjustment outlined.

'Listening to' clients involves staff seeing the client not just in terms of the 'problems' they are presenting but as a whole person. It involves respect for that person, and their role in their own recovery. However, this also requires resources for staff, the time to take a more proactive approach to care. A practical example for one element of this is in a mental health service described by Thomas and Leck (1997) where clients on the ward were asked to write their life histories, giving as much information as they wanted with support in writing, if required, to enable staff to develop a more holistic view of clients. This was introduced alongside other measures and although standardised measures had not been employed to evaluate the effects of changes on the ward, staff reported that they were taking a more individual approach to rehabilitation.

#### **4.5.2 Social Implications**

An aspect consistently highlighted by clients was the importance of time in recovery. This required appropriate social support, however one impact of the experience of psychotic symptoms often seemed to be the breakdown of the relationships that could have provided that support. Practical support was highlighted as particularly important during the early stages of the adjustment process, such as appropriate accommodation. For younger participants this often meant returning to the parental home, and therefore it seems important for services to support families in this transition, and in 'caring' for the client at this time. For clients who are older at the onset of mental illness, and for some younger clients, this option is not available or desirable and therefore assessment of accommodation needs and suitable accommodation provision is vital (Lavender and Watts, 1994). One participant highlighted the supportive

residential accommodation that she moved into after her initial discharge from hospital as the most important element in her recovery. Assessment of and provision for the social needs of clients involves seems to require flexibility of services. Using the example of accommodation, this may mean providing support to families, or providing accommodation that can be flexible to the persons needs, in this study family friendly policies were highlighted as important for women with children.

#### **4.5.3 Psychological Implications**

The process of adjustment involves a rebuilding of life, a crucial part of this is evaluation and reflection on experiences. The talking therapies were outlined by participants who had access to them as very helpful to this process. They emphasised the importance of being able to build up a picture of what had occurred, and being supported in making changes to their lives. One way of assisting clients in building this picture could be through the use of narrative therapy, developed by White (1987). A main assumption of narrative therapy is that individuals can define their life in many ways, and an aim is to build on their strengths. Narrative therapy can be used on an individual basis, but also through group work. Groups were identified by clients as a useful medium especially in the earlier stages of adjustment when clients found it difficult to reflect on their own experiences, but could perhaps gain inspiration from other users experiences. It may also assist the social comparison processes highlighted earlier as other users in the group validate each others experiences without judgement giving an opportunity for respect, equality and listening, which were highlighted as important especially in the third stage of adjustment. In the later stages a group can be used to help to develop a 'narrative' about what has occurred, and support people in rebuilding their lives using their own strengths and resources (Vassalo, 1998).

The identification of strengths and resources is a vital part of the therapeutic process, specifically impacting on the process of acceptance. There is some evidence that acceptance of the label or illness contributes to a positive clinical outcome (McGlashan and Carpenter, 1981). This has led to recommendations for therapy to include encouraging clients to recognise their difficulties (Appelo et al, 1993). However, the present study suggested that acceptance was associated with a negative impact on the self, including feelings of depression, anxiety, and a poor self image. A sense of mastery, which included identification of strengths and resources, seemed to impact positively on these feelings, and the therapeutic process should aim to build on this.

#### **4.6 Research Implications**

“It could indeed be that the scientific scenario of ‘demonstrably effective procedures’ and ‘empirically confirmed fact’ so characteristic of evidence-based medicine is not all there is to helping recovering psychotic people, and indeed may not even be the most important thing at all.” (Chadwick, p.583, 1997).

The increasing emphasis on evidence based practice, and the outcome measures used in evaluation and audit of services to measure the extent to which services objectives have been met do not seem to take into account fully the objectives of the participants voiced in the present study. For the majority of participants recovery seemed to mean the ability to live their lives the best they could, for some this included a reduction in symptoms, but for others symptoms were accepted as a part of this life, and the aim was to live productively alongside these symptoms. Traditional outcome measures, for example assessment of symptom reduction, may not be valid measures of recovery in this context and tools that measure quality of life may be more appropriate (Oliver et al., 1996).

Some of the difficulty for research in this area arises from confusion over what the term recovery means, but also from the differing values placed on outcome. One way of incorporating users views into the assessment of recovery is the increasing body of research being produced by the user movement itself. Also the dovetailing of qualitative and quantitative methods (Chadwick, 1997). Qualitative methods can be used as in this study to identify what is important to the user, for example controllability, and quantitative research methods used to investigate it further and produce generalisable findings.

Tentative findings were suggested regarding the impact of sociodemographic variables on the process of adjustment. The impact of age of onset was discussed earlier in relation to the process of adjustment. There is an increasing body of research into early onset psychosis, and it would be interesting to relate this to the process of adjustment. Another intervening factor on the process of adjustment seemed to be the impact of culture, which was highlighted by some participants, specifically the area of labelling and culture. Ethnographic research into this, and implications for services would be useful. Another characteristic that came up in this research as maybe being pertinent was gender. The findings that women's recovery process may be faster, but that the psychological processes they engage in may result in increased distress such as hopelessness require further research. Gender has also been found to have an effect on the subjective experience of schizophrenia. Roeder, Ute, and Priebe (1998) found that gender plays a role in subjective satisfaction with life in certain domains and they suggested that perhaps appraisal processes of men and women differ in these domains. This research provided tentative support for their findings but Kulkarni (1997) states that there is an overall lack of gender-based research in schizophrenia and that in order to understand better the impact of schizophrenia on women, such research is necessary.

The aim of developing a theoretical model for the process of adjustment was to develop understanding of the process of recovery. Replication of a similar study with another group would be useful. One of the main suggestions of the model was that in the final stage of adjustment a choice is made about how to move forward, and make adjustments to life. The experiences and processes in the preceding stages of the model seemed to lead to this choice, but currently only tentative suggestions about how they impact on this choice can be made. Further research on the factors that influence the final stage of adjustment would be useful. In addition, this study did not explore pre morbid influences on the process of adjustment, and this may be a fruitful area to focus on in further research to outline possible predictive variables of adjustment to enhance care planning.

#### **4.7 Conclusions**

This study has proposed a temporal stage model of the process of adjustment to the experiences of psychosis, and the diagnosis of schizophrenia. Although, the attributions people make about their experiences, and what is helpful to the recovery process, are individual, the interviews seemed to elicit some commonality of the psychological processes that are engaged in to adjust to these experiences. This study also suggested that adjustment to the actual diagnosis of schizophrenia, and the psychological and social consequences of that diagnosis is as vital, or even more so, than the psychological adjustment to the experiences of psychosis. This study has highlighted the importance of a person orientated approach within mental health services at all levels; medical, social and psychological, to assist in the process of adjustment. It has also highlighted the importance of wider social systems to the process of adjustment. The main clinical implication of this research is to provide a useful explanatory framework for the adjustment process, which may aid professionals working within mental health services in

taking a holistic approach to the individual going through a process of experiencing and recovering from psychosis.



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## **Appendix 1 – Health of the Nation Outcome Scale**

# HoNOS

## Health of the Nation Outcome Scales



## Glossary for HoNOS Score Sheet

HoNOS: August 1996

Authors: J. K. Wing, R. H. Curtis, A. S. Beevor  
Royal College of Psychiatrists Research Unit,  
11 Grosvenor Crescent, London SW1X 7EE  
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*Rate 9 if not known*

### 2. Non-accidental self-injury

- Do not include accidental self-injury (due e.g. to dementia or severe learning disability); the cognitive problem is rated at Scale 4 and the injury at Scale 5.
  - Do not include illness or injury as a direct consequence of drug/alcohol use rated at Scale 3 (e.g. cirrhosis of the liver or injury resulting from drink driving are rated at Scale 5).
- 0 No problem of this kind during the period rated.
  - 1 Fleeting thoughts about ending it all but little risk during the period rated; no self-harm.
  - 2 Mild risk during the period rated; includes non-hazardous self-harm (e.g. wrist-scratching).
  - 3 Moderate to serious risk of deliberate self-harm during the period rated; includes preparatory acts (e.g. collecting tablets).
  - 4 Serious suicidal attempt and/or serious deliberate self-injury during the period rated.

*Rate 9 if not known*

### 3. Problem-drinking or drug-taking

- Do not include aggressive/destructive behaviour due to alcohol or drug use, rated at Scale 1.
  - Do not include physical illness or disability due to alcohol or drug use, rated at Scale 5.
- 0 No problem of this kind during the period rated.
  - 1 Some over-indulgence but within social norm.
  - 2 Loss of control of drinking or drug-taking, but not seriously addicted.
  - 3 Marked craving or dependence on alcohol or drugs with frequent loss of control, risk taking under the influence.
  - 4 Incapacitated by alcohol/drug problem.

### Summary of rating instructions:

- 1) Rate each scale in order from 1 to 12
- 2) Do not include information rated in an earlier item except for item 10 which is an overall rating
- 3) Rate the MOST SEVERE problem that occurred during the period rated
- 4) All scales follow the format:
  - 0 = no problem
  - 1 = minor problem requiring no action
  - 2 = mild problem but definitely present
  - 3 = moderately severe problem
  - 4 = severe to very severe problem

*Rate 9 if not known*

### 1. Overactive, aggressive, disruptive or agitated behaviour

- Include such behaviour due to any cause, e.g. drugs, alcohol, dementia, psychosis, depression, etc..
  - Do not include bizarre behaviour rated at Scale 6.
- 0 No problem of this kind during the period rated.
  - 1 Irritability, quarrels, restlessness etc. not requiring action.
  - 2 Includes aggressive gestures, pushing or pestering others; threats or verbal aggression; lesser damage to property (e.g. broken cup, window); marked overactivity or agitation.
  - 3 Physically aggressive to others or animals (short of rating 4); threatening manner; more serious overactivity or destruction of property.
  - 4 At least one serious physical attack on others or on animals; destructive of property (e.g. fire-setting); serious intimidation or obscene behaviour



**Rate 9 if Not Known**

**4. Cognitive problems**

- *Include problems of memory, orientation and understanding associated with any disorder: learning disability, dementia, schizophrenia, etc.*
  - *Do not include temporary problems (e.g. hangovers) resulting from drug/alcohol use, rated at Scale 3.*
- 0 No problem of this kind during the period rated.  
1 Minor problems with memory or understanding (e.g. forgets names occasionally).  
2 Mild but definite problems (e.g. has lost the way in a familiar place or failed to recognise a familiar person); sometimes mixed up about simple decisions.  
3 Marked disorientation in time, place or person; bewildered by everyday events; speech is sometimes incoherent; mental slowing.  
4 Severe disorientation (e.g. unable to recognise relatives), at risk of accidents; speech incomprehensible; clouding or stupor.

**Rate 9 if Not Known**

**5. Physical illness or disability problems**

- *Include illness or disability from any cause that limits or prevents movement, or impairs sight or hearing, or otherwise interferes with personal functioning.*
  - *Include side-effects from medication; effects of drug/alcohol use; physical disabilities resulting from accidents or self-harm associated with cognitive problems, drink-driving, etc.*
  - *Do not include mental or behavioural problems rated at Scale 4.*
- 0 No physical health problem during the period rated.  
1 Minor health problems during the period (e.g. cold, non-serious fall, etc.).  
2 Physical health problem imposes mild restriction on mobility and activity.  
3 Moderate degree of restriction on activity due to physical health problem.  
4 Severe or complete incapacity due to physical health problem.

**Rate 9 if Not Known**

**6. Problems associated with hallucinations and delusions**

- *Include hallucinations and delusions irrespective of diagnosis.*
  - *Include odd and bizarre behaviour associated with hallucinations or delusions.*
  - *Do not include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions, rated at Scale 1.*
- 0 No evidence of hallucinations or delusions during the period rated.  
1 Somewhat odd or eccentric beliefs not in keeping with cultural norms.  
2 Delusions or hallucinations (e.g. voices, visions) are present, but there is little distress to patient or manifestation in bizarre behaviour, i.e. clinically present but mild.  
3 Marked preoccupation with delusions or hallucinations, causing much distress and/or manifested in obviously bizarre behaviour, i.e. moderately severe clinical problem.  
4 Mental state and behaviour is seriously and adversely affected by delusions or hallucinations, with severe impact on patient.

*Rate 9 if Not Known*

**8. Other mental and behavioural problems**

- *Rate only the most severe clinical problem not considered at items 6 and 7 as follows.*
  - *Specify the type of problem by the entering the appropriate letter:  
A phobic; B anxiety; C obsessive-compulsive;  
D mental strain/tension; E dissociative; F somatoform.  
G eating; H sleep; I sexual; J other, specify.*
- 0 No evidence of any of these problems during period rated.
  - 1 Minor non-clinical problems.
  - 2 A problem is clinically present at a mild level (e.g. patient has a degree of control).
  - 3 Occasional severe attack or distress, with loss of control (e.g. has to avoid anxiety provoking situations altogether, call in a neighbour to help, etc.) i.e. moderately severe level of problem.
  - 4 Severe problem dominates most activities.

*Rate 9 if Not Known*

**7. Problems with depressed mood**

- *Do not include overactivity or agitation, rated at Scale 1.*
  - *Do not include suicidal ideation or attempts, rated at Scale 2.*
  - *Do not include delusions or hallucinations, rated at Scale 6.*
- 0 No problem associated with depressed mood during the period rated.
  - 1 Gloomy; or minor changes in mood.
  - 2 Mild but definite depression and distress (e.g. feelings of guilt; loss of self-esteem).
  - 3 Depression with inappropriate self-blame, preoccupied with feelings of guilt.
  - 4 Severe or very severe depression, with guilt or self-accusation.

*Rate 9 if Not Known*

**9. Problems with relationships**

- *Rate the patient's most severe problem associated with active or passive withdrawal from social relationships, and/or non-supportive, destructive or self-damaging relationships.*
- 0 No significant problems during the period.
  - 1 Minor non-clinical problems.
  - 2 Definite problems in making or sustaining supportive relationships: patient complains and/or problems are evident to others.
  - 3 Persisting major problems due to active or passive withdrawal from social relationships and/or to relationships that provide little or no comfort or support.
  - 4 Severe and distressing social isolation due to inability to communicate socially and/or withdrawal from social relationships.

## Rate 9 if Not Known

### 12. Problems with occupation and activities

- *Rate the overall level of problems with quality of day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, access to supportive facilities, e.g. staffing and equipment of day centres, workshops, social clubs, etc.*
  - *Do not rate the level of functional disability itself, rated at Scale 10.*  
**NB: Rate patient's usual situation. If in acute ward, rate activities during period before admission. If information not available, rate 9.**
- 0 Patient's day-time environment is acceptable: helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.
  - 1 Minor or temporary problems (e.g. late giro cheques; reasonable facilities available but not always at desired times, etc.).
  - 2 Limited choice of activities, e.g. there is a lack of reasonable tolerance (e.g. unfairly refused entry to public library or baths etc.); or handicapped by lack of a permanent address; or insufficient carer or professional support; or helpful day setting available but for very limited hours.
  - 3 Marked deficiency in skilled services available to help minimise level of disability; no opportunities to use intact skills or add new ones; unskilled care difficult to access.
  - 4 Lack of any opportunity for daytime activities makes patient's problems worse.

## HoNOS Score Sheet

### Scale 0-4

### Rate 9 if not known

1	Overactive, aggressive, disruptive or agitated behaviour	<input type="checkbox"/>	<input type="checkbox"/>
2	Non-accidental self-injury	<input type="checkbox"/>	<input type="checkbox"/>
3	Problem-drinking or drug-taking	<input type="checkbox"/>	<input type="checkbox"/>
4	Cognitive problems	<input type="checkbox"/>	<input type="checkbox"/>
5	Physical illness or disability problems	<input type="checkbox"/>	<input type="checkbox"/>
6	Problems with hallucinations & delusions	<input type="checkbox"/>	<input type="checkbox"/>
7	Problems with depressed mood	<input type="checkbox"/>	<input type="checkbox"/>
8	Other mental & behavioural problems (specify A, B, C, D, E, F, G, H, I or J)	<input type="checkbox"/>	<input type="checkbox"/>
9	Problems with relationships	<input type="checkbox"/>	<input type="checkbox"/>
10	Problems with activities of daily living	<input type="checkbox"/>	<input type="checkbox"/>
11	Problems with living conditions	<input type="checkbox"/>	<input type="checkbox"/>
12	Problems with occupation and activities	<input type="checkbox"/>	<input type="checkbox"/>
<b>Total Score (0-48)</b>		<input type="checkbox"/>	<input type="checkbox"/>

## Rate 9 if Not Known

### 10. Problems with activities of daily living

- *Rate the overall level of functioning in activities of daily living (ADL): e.g. problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development, etc.)*
  - *Include any lack of motivation for using self-help opportunities, since this contributes to a lower overall level of functioning.*
  - *Do not include lack of opportunities for exercising intact abilities and skills, rated at Scales 11-12.*
- 0 No problems during period rated; good ability to function in all areas.
  - 1 Minor problems only (e.g. untidy, disorganised).
  - 2 Self-care adequate, but major lack of performance of one or more complex skills (see above).
  - 3 Major problems in one or more area of self-care (eating, washing, dressing, toilet) as well as major inability to perform several complex skills.
  - 4 Severe disability or incapacity in all or nearly all areas of self-care and complex skills.

## Rate 9 if Not Known

### 11. Problems with living conditions

- *Rate the overall severity of problems with the quality of living conditions and daily domestic routine. Are the basic necessities met (heat, light, hygiene)? If so, is there help to cope with disabilities and a choice of opportunities to use skills and develop new ones?*
  - *Do not rate the level of functional disability itself, rated at Scale 10.*  
**NB: Rate patient's usual accommodation. If in acute ward, rate the home accommodation. If information not available, rate 9.**
- 0 Accommodation and living conditions are acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.
  - 1 Accommodation is reasonably acceptable although there are minor or transient problems (e.g. not ideal location, not preferred option, doesn't like the food, etc.).
  - 2 Significant problem with one or more aspects of the accommodation and/or regime (e.g. restricted choice: staff or household have little understanding of how to limit disability, or how to help use or develop new or intact skills).
  - 3 Distressing multiple problems with accommodation (e.g. some basic necessities absent); housing environment has minimal or no facilities to improve patient's independence.
  - 4 Accommodation is unacceptable (e.g. lack of basic necessities: patient is at risk of eviction or 'roofless'; or living conditions are otherwise intolerable) making patient's problems worse.

## **Appendix 2 – Interview Schedule**

- Any questions about the study/information sheet. Reiterate that able to stop any time, and points about confidentiality.
- Sign consent form.

I understand that you've had some experiences, some difficulties, that have led you to come into contact with mental health services. I'm interested in how you've made sense of these experiences, and the effect they've had on your life.

I'd like to start the interview by asking for some general background information.

1. So perhaps, could you begin by telling me about your current circumstances.

Prompt: Can you tell me about the nature of your experiences/difficulties at the moment?

### **Areas to cover**

Current experiences/difficulties

Demographic information – living situation, employment.

2. Now I'd like to go back a bit, and ask when did you first come into contact with services?  
What was life like at that time?

### **Areas to cover**

First recognition of symptoms

Meaning given to those symptoms

Roles played by other people

Work back from this point with the aim of getting information on life before experiencing mental health problems, and then work forward covering the following areas using a life story, only asking following questions if necessary.

3. How did you first come into contact with services?

### **Areas to cover**

Description of events. Prompt: What happened?

Feelings about hospital admission (if appropriate)

4. How the doctors/nurses seem to make sense of these experiences?

Prompt: What kind of explanation did you receive of what you had been experiencing?

### **Areas to cover**

Whether a diagnosis was given

How a diagnosis was given

How much information was given

How useful this experience was

What would have been helpful

5. What has been the effect of these experiences on how you live your life?

**Areas to cover**

Prompts: What was life like before you came into contact with services/started having these experiences?

At that time, what were your plans for the future?

How have these changed?

Work

Family

Friendships

Living situation

6. What has been the effect of these experiences on how you view yourself?

**Areas to cover**

Meanings of different experiences. Prompt: What do you think caused these experiences to happen?

Feelings associated with experiences

How coped with different experiences

Role of other people (friends, family and society)

7. What has been your experiences of health services since you came into contact with them?

**Areas to cover**

Positive and negative experiences of services?

Views on service development

**Debriefing**

We've finished the interview now.

1. Could you tell me how you feel now we've finished the interview?
2. How did you find talking to me about these issues?
3. Has taking part raised any particular issues for you?
4. Finally, I wondered whether you had any questions, or whether there was anything not covered in the interview that you would like to talk about now?

Thank you very much for taking part in this interview. It will help my understanding of how people make sense of these types of experiences, and what could help. If any issues arise, or any questions that you were unable to ask today, my phone number is on the information sheet so please call, and if I'm not there, leave a message and I'll call you back.

### **Appendix 3 – Ethical Approval**

**RESEARCH ETHICS COMMITTEE**

Ms Joanna Seller

Dear Ms Seller,

**RREC 2159 - A study investigating the impact of, and the process of adjustment to, a diagnosis of Schizophrenia.**

I am writing to inform you that this study has been considered and approved by the Committee.

Please note the following conditions which form part of this approval:

- [1] **This approval is for one year only.** For projects with an expected duration of more than one year, a letter from the principal investigator will be required in order to further extend consent. This will enable the Committee to maintain a full record of research.
- [2] Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee's approval.
- [3] The Committee should be notified immediately of any serious adverse events that are believed to be study related or if the entire study is terminated prematurely.
- [4] You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, e.g., extra work for laboratories. Approval by the Committee for your project does not remove your responsibility to negotiate such factors with your colleagues.
- [5] You must ensure that nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

Cont/2..

**Cont2/.. RREC 2159 - A study investigating the impact of, and the process of adjustment to, a diagnosis of Schizophrenia.**

- [6] Pharmacy must be told about any drugs and all drug trials, and must be given the responsibility of receiving and dispensing any trial drug.
- [7] The Committee must be advised when a project is concluded and should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.
- [8] All documents relating to the study, including Consent Forms for each patient (if applicable), must be stored securely and in such a way that they are readily identifiable and accessible. The Committee will be conducting random checks on the conduct of studies, and these will include inspection of documents.

May I take this opportunity to wish you well in your research. If any doubts or problems of an unexpected nature arise, please feel free to contact me at any time.

Yours sincerely



**C G Mackworth Young MA MD FRCP  
Chairman - RREC**

<b>Seen and Approved</b>	
<b>Submission</b>	<b>19<sup>th</sup> July, 1999</b>
<b>Protocol</b>	<b>-</b>
<b>Information Sheet</b>	<b>30<sup>th</sup> September 1999 Version 2</b>
<b>Consent Form</b>	<b>Yes</b>
<b>Questionnaires</b>	<b>Semi structured interview schedule.</b>
<b>Letter of Indemnity</b>	<b>-</b>
<b>CTX/DDX/Licence</b>	<b>-</b>



## **Appendix 4 – Participant Information Sheet**

### **Address of CMHT**

### **Patient Information Sheet**

#### **'The impact of mental health problems'**

#### **Introduction**

This study is being carried out by Joanna Seller, Psychologist in Clinical Training, and supervised by Professor Tony Lavender who is a Clinical Psychologist with extensive experience in working with people experiencing mental health problems.

#### **What is this study about?**

I am interested in how mental health problems have affected your life, and how you have dealt with the impact of them.

#### **What will happen during the study?**

The study will involve an interview.

The interview will be audiotaped so that I can listen to what you are saying rather than taking notes.

The interview should last no longer than an hour.

#### **What is the purpose of doing this research?**

By paying more attention to the effect on you of your experiences it is hoped that we can gain a better understanding of what may be helpful to you, and other people with mental health problems.

#### **What if I refuse to take part or stop halfway through?**

That is fine; your treatment will not be affected in any way. If you find this distressing at any stage you can stop the interview.

#### **What about confidentiality?**

All material will be held in confidence and will be used for research purposes only. Audio tapes will only be listened to by me and my supervisor. They will then be erased. Your views will be written up, but no one will be able to tell who was interviewed.

You do not have to take part in this study and can stop the interview at any time; it is your right to do so. This will not affect the service you receive in any way.

#### **Who should I contact if I have any concerns?**

After the interview if you want any further information, or if anything is unclear, you can contact Joanna Seller at the Salomons Centre (Tel: 01892 507666).

## **Appendix 5 – Consent Form**

### **RESEARCH CONSENT FORM**

**Address of CMHT**

**Title of Project: The impact of mental health problems**

Have you read the Patient Information Sheet? Yes No

Have you had the opportunity to ask questions and discuss this study? Yes No

Have you received satisfactory answers to all of your questions? Yes No

Have you received enough information about the study? Yes No

Who have you spoken to (write name)?

Do you understand that you are free to withdraw from the study:  
at any time; without having to give a reason;  
without affecting your future medical care? Yes No

Do you agree to take part in this study? Yes No

**NAME IN BLOCK LETTERS:**

Signed: Date:

**NAME OF DOCTOR:**

Signed: Date:

## Appendix 6 – Research Diary

06/10/99

Decided to start keeping a research diary, as have received ethical approval and feel like dissertation has really started now. Spent some time today developing interview schedule, incorporating some of the ideas from adjustment to physical illness literature (e.g. Beliefs about the cause of difficulties). Also spent some time thinking about introducing the research to participants, and ethical issues related to the interviews. I am concerned about the differences between therapeutic and research interviews.

17/10/99

Comments from others on my interview schedule seemed to say that my initial questions were too broad. The first section asks about current circumstances, just to set the context in which to talk, and also to get an idea of the language they use to describe their difficulties. However, it seems that they will not necessarily start to talk about mental health difficulties, so the second section asking about when they first started experiencing them, does not really make sense. It seems better to be more specific – “When did you first come into contact with services” and then start to ask questions about this time. I also did a pilot interview with a fellow trainee, with her role playing a client, and that seemed to work better but the interview seemed to leave out a big chunk of time which may effect the process of adjustment. It seems therefore that a good way of conducting the interview may be to use a life story approach, trying to cover effects of experiences on life and self through talking about what has happened. I actually think though that the interview will flow better when someone is actually talking about their own experiences. However, I am concerned that I will not explore fully enough the important parts.

07/11/99

Went to meet team where I am doing the research, was late due to train strikes, bit of a nightmare really! The enormity of what lies ahead hit me today as I was explaining to team members, and I am unsure whether I will ever complete it. I used to work there and most of the team has changed, but they were willing to help. What was good was that they felt the research would be really useful, and were really keen on the idea. However, some of them seemed to think it would be difficult to get participants because of the short time span since diagnosis required. They agreed to spend some time thinking of potential participants from their caseload and I am going back next week to get names and decide with them the best way to approach participants. I think it is going to be harder than I hoped. Someone also brought up the issue of travel expenses for participants which made me think about perhaps carrying out some interviews at peoples homes but that throws up a number of issues such as safety, appropriateness etc.

14/11/99

Went to do a pilot study, and after my explanation of the study he refused. This was after a lot of effort to co-ordinate with his out patient appointment and this increased my anxiety about how I will be able to complete the research in the time allocated. However, the process of actually presenting the research to a participant and discussing the study calmed some of my other anxieties. One of my major worries was that this interview would upset people. The reason this participant gave for not participating was that he would find it too distressing, thinking back on what happened to him would be upsetting. It has reassured me that people feel able to refuse, and has allowed me to let them take some responsibility for how the

interview may make them feel. Also while I was there one of the team members rang a potential participant and I was very pleased with the way he explained the study, reiterating that even if the man agreed to participate, he can stop at any time for any reason. Ethically therefore I feel more confident. Hopefully I have my pilot study next Thursday. I have spoken to him on the phone and he sounds quite keen.

30/11/99

Since last writing in this diary I have done 3 interviews. The pilot study that I was hopeful about did not go very well, although it was useful as a pilot study. The participant it turned out had received a diagnosis of schizophrenia 12 years ago, and found remembering back to that time extremely difficult. It was also very hard as it was such a long time ago to elicit the information I wanted from a life story narrative approach in one interview as the process was so long! I sent the tape to Tony (my supervisor) with much embarrassment, and he noted that sometimes my tone was too social, and that I had a tendency to jump in with my reaction to what the person was saying which may prevent the participant from giving their true thoughts on the subject. I agree with this, and am finding it difficult to settle to a research interview that is different from a clinical interview for therapy, but also different from a more social exchange. I think I need to focus on saying less, allowing more silence and to tune in more to the effect the interview is having on the person.

The second interview went much better. This participant was diagnosed just 2 years ago and it was a useful and interesting interview. He seemed engaged in the process of adjustment, and aware of it. His psychiatrist has a special interest in clients with a recent onset of psychosis, and it sounded like she had been very supportive. I recently attended a child psychotherapy workshop about looked after children, and one of the main points to come out was the importance of one relationship with a professional in which the child was held in mind during the transition period, e.g. leaving care to adoption. I wondered about the effect of this on someone adjusting to a schizophrenia diagnosis, another type of transition. Although the interview was very interesting and was a positive experience I felt afterwards that it did not seem to fit with my thoughts about the adjustment process, and I wasn't sure whether it answered any of my questions. As I'm writing this I'm thinking about how I need to bear in mind what my research questions are as I'm carrying out the interviews.

The third interview was disastrous. I think that I may not have communicated my criteria very well as it turned out the participant's first contact with mental health services had been in 1972. He was so keen to do the interview, that I carried on just keeping it short knowing that I would be unable to use it. However he then disclosed some suicidal intentions and I spent the next hour doing a form of risk assessment. This experience has built up my confidence in handling difficult situations in a research context! I got his consent to feedback to his Keyworker, who then arranged to make contact with him the next day.

Talking to Tony about the interviews not yielding useful information, he asked me to talk through some of the themes that had emerged from interview 2 – support of parents, feelings of guilt and letting people down, the spectrum of mental illness- and this pointed out to me again the nature of qualitative research, that it is exploratory and is not there to confirm my own views! We also discussed the defensiveness with which participants talked about certain subjects, but apparently that's discourse analysis.

09/12/99

Have carried out another interview where there was some more talking about guilt and shame – where does this fit it? I am in the process of transcribing, and interesting points are emerging about the need to build up a picture of what has happened – may fit well with narrative therapy. It is difficult getting participants, a slow process.

06/01/00

Christmas and new year out the way – had a good break and now nose to the grindstone. Went to do an interview today who was supposed to attend with a support worker but did not turn up so complete waste of time. I think I need to rethink my approach to arranging interviews. While transcribing I start thinking about uncertainty as one of the early emotions associated with a mental health problem.

07/01/00

Transcribing again and there seems to be a sense of ‘life going nowhere’. This also seems to be related to the stage of life that schizophrenia happens for some people – late adolescence, early adulthood- when a lot of changes should be happening and it stops them. Wondering about other research in effects of age of onset on illness adjustment.

06/02/00

Having a lot of difficulty getting participants, specifically women who are less likely to consent. Why? Have done 2 more interviews both in wholly unsuitable environment but I had little choice. One was in the utility room of a hostel with the tumble drier on (great for transcribing!) and as I discovered during the interview (when someone tried to come in) you could only open the door from the inside. However, they had issued me with a personal alarm when I entered the hostel, however what they would do if I used it I was not sure since I was locked in a room. The other interview was carried out on a ward in their only interview room. This was basically a cupboard that contains the ECT equipment – not exactly a neutral environment! In our advanced reading seminars on psychosis we are aware that we are getting into the habit of ‘system bashing’. However it is extremely hard not to get into this. I have been away from these wards for nearly 3 years and coming back nothing has changed except they are now locked and lilac! If anything the chaos and sense of confusion is worse. In these interviews I noticed a theme of control and have been thinking about how much more difficult it is to adapt when you have so little control (e.g. being locked in, the effect of sectioning, compulsory medication). And also the way that ‘treatment’ or mental health services pervade people’s whole lives (e.g. where they live – hostels). Wondering how lack of control fits in with the cognitive models of adjustment and coping.

10/02/00

More transcribing and initial analysis today. I was struck again today by what a difficult age psychosis can start at – when people are often still dependant – just starting to break away from their parents. One of the effects is that their parents are involved in their admission to hospital. This is a shattering blow to that attachment relationship. The involvement of friends and family in treatment seems crucially important to adjustment.

16/02/00

Transcribing – always seems to be other people’s idea to contact mental health services. What effect does that have?

02/03/00

Had an extremely interesting interview today which seemed to suggest a movement over time from a position of helplessness to one of power and choice. This woman had recently become involved in MIND, and was becoming quite involved with the user movement. Could this gradual process have been speeded up by anything from within mental health services? The interview concluded with her saying that although the experience of psychosis had been negative and distressing, the effects of it had been positive. She found it a really useful experience, pointing out how much easier it is to think about these issues when someone asks

you than alone. My fears about the distressing nature of the interviews appear to have been unfounded as most people have reported in debriefing that they found it overall to be a useful experience.

17/03/00

Was struck yesterday after interviewing a 23 year old woman who had started suffering psychosis at 17 how immature she appeared (similar to first woman interviewed). How difficult it was for her to answer questions about rebuilding life. If psychosis happens while you are in the process of forming an adult identity, how much harder it then is to rebuild that identity when there was barely one there to start with. You have to start from scratch but in a very disadvantaged position – not at an ideal time with all the subsequent difficulties that a mental illness brings.

I have also been writing my introduction about the role of social comparison processes in building up self esteem (e.g. In cancer – ‘I’m not as ill as her.’). However in mental illness it may have the opposite effect reducing hope (e.g. ‘Will I become like that?’). Also the role the media plays in that people with schizophrenia are not portrayed as battling against the odds as people with cancer are. It also seems that women talk more about comparing themselves to others than men.

28/03/00

Completed my last interview yesterday. I felt a mixture of relief, but also that I should have asked more about certain subjects. I have been analysing an interview today line by line, noticed the role that medication plays in recovery, i.e. what taking it or not taking it means to the person. I then wished I’d asked about what that means for people to have their medication reduced as I’m wondering whether that is seen as a concrete sign of recovery. Perhaps ideas about this will come out from the data I’ve got already. I did do the interviews in 2 waves, men then women and am analysing in the same way. There does seem to be a tendency for men to externalise the cause of their mental health problems and I pursued this more with women who seem to blame themselves more, and see it more as an internal thing related to personality.

29/03/00

When start experiencing mental health problems in adolescence parents seem to interpret symptoms as normal adolescence – e.g. not getting up on time, being rude, and therefore apply more pressure. Whereas if the person is older, parents or family see behaviour as a change from ‘normal’ personality and perhaps encourage them to seek help earlier.

09/04/00

Although nearly everybody has causal beliefs some have more than one, and I’m wondering how that effects recovery – how do you exert more control over lots of things. For example one man talked about cannabis, isolation and drinking as all potential causes of his mental health difficulties. As people tend to try and avoid doing what they felt caused the difficulties, having a lot of potential causes makes that difficult.

For older participants many say the loss of role is very hard, especially for women from carer to someone cared for.

01/05/00

Carrying on with analysis and memo writing such as in order to be able to use help offered by others, implicit in this statement is that you need to be able to trust them. One of the effects of experiences from mental illness is a reduced trust in others therefore its difficult to allow them

to help you. This could be a vicious cycle, with not allowing others to help as do not trust them, therefore perceiving others as not helpful and trusting them less.

11/05/00

What people seem to be saying in the interviews is that although what is happening to them is at least just as bad but probably worse than what has gone before, they are finding it easier to cope with – they are experiencing it as easier. A number of reasons are outlined for this one – time, and another learning, the role of learning strategies to cope which presumably is linked with time. This may also include acceptance, which is discussed by a lot of people.

26/05/00

Linking things together more now, which involves drawing a lot of diagrams. However, I am now finding that I can explain perfectly what I want to say with a diagram but it is then difficult to translate that to the written word. I don't think I can just hand in a set of pictures! Again thinking about the role of medication – it does seem to be used as concrete evidence for getting better. Whereas with an illness like cancer there are x rays and cell counts to monitor progress, in mental illness there is only subjective feeling and so the doctor's decision to reduce or increase medication are given a huge amount of significance which may explain part of the huge urge people have to have medication reduced, as a sign of hope.

09/06/00

Still analysing! There seems to be a lot about not being heard or understood by mental health services. This falls under a lot of different categories at the moment, and I think it deserves a category of its own. Something I have learnt from this research if I ever was to do qualitative research again is to write all my memos in one place. Currently I either write them here, in my 'research book' or on NUD.IST, which I am beginning to realise, is very time consuming.

23/06/00

I am putting it all together now with even more complicated diagrams and enormous amounts of arrows. The task is to make it understandable to everyone else. Writing the results with the quotes has been good as it brings you back to the data and reminds me what it was that led to all these categories and inter relationships.

05/07/00

Finishing results, and writing discussion, and trying to hold a lot of information in my mind at one time. I have sent off my summary to participants who agreed to do it and I am just waiting for their reply hopefully – although I am aware I have not left them much time. It's all such a rush now.

## **Appendix 7 – List of codes and categories generated by analysis**

This is a summary of the codes and categories, for the five stages of the adjustment process, developed from the interviews with participants. The central category or stage of the adjustment process are in bold in uppercase letters, and the categories that make up that stage are written in bold with any subcategories underlined, and codes listed beneath categories and subcategories. The number in brackets refers to the number of participants whose response was included within that particular code.

### **1. STAGE 1 – BECOMING DIFFERENT**

#### **Self becoming aware**

Limited awareness (6)

Beliefs (5)

#### **Action by self**

Difficulty seeking outside help (3)

Self help (2)

#### **Others becoming aware**

Family (6)

Friends (3)

Wider systems (4)

#### **Action by others**

Helpseeking (6)

Action to the person (4)

#### **Lack of control**

Lack of control (3)

Others taking control (2)

#### **Intervening Condition**

Lack of support (4)



## **STAGE 2: INITIAL REACTIONS**

### **Reaction to Diagnosis**

Shock (2)

Lack of understanding (6)

Denial (5)

### **Reaction to Treatment**

Anger (5)

Isolation (4)

Wish to escape (2)

### **Reaction to Psychotic experiences**

Distress (2)

Social Comparison (2)

### **Increasing awareness**

Awareness (4)

Information/explanation seeking:

'Getting better' (3)

Limited explanations (3)

Limits of the medical model (5)

### **Sense of Powerlessness (3)**

### **STAGE 3: BEGINNING RECOVERY**

#### **Process of Gradual acceptance**

Starting acceptance (6)

Reduction of denial (3)

Accepting help (3)

Importance of Equality and respect (3)

Importance of talking therapies (8)

#### **Rumination**

Distress (2)

Self blame (4)

#### **Positivity**

Positive feelings (4)

Desire for independence (2)

Effect of labelling and stigma (4)

#### **Lack of Control**

Uncertainty (2)

#### **Time to recover**

Not working (3)

Recovery from symptoms (2)

Recovery from experiences (2)

Service provision (3)

#### **Intervening Conditions**

Experiences of Communication

Progress (4)

Medication (3)

Prognosis (3)

## **STAGE 4: COMING TO TERMS**

### **Gathering Information**

Information on diagnosis (2)

Information on treatment (4)

Sources of information (5)

### **Reflection**

Role of reflection (5)

### **Evaluation**

Own responsibility (4)

Others role in evaluation (2)

### **Forming Causal Beliefs**

External (10)

Internal (4)

Attributions of control (6)

### **Acceptance**

Acceptance of diagnosis

Acceptance (2)

What to accept of diagnosis (4)

Acceptance of loss:

Loss of relationships (4)

Loss of future plans (3)

Loss of work (2)

### **Intervening variables**

Effect of social comparison (3)

Effect of stigma (5)

Importance of talking therapies (3)

## **STAGE 5: ACCEPTANCE AND LIFESTYLE CHOICE**

### **Get better – pursue normal life**

Role of Understanding and support (2)

Rebuilding identity (5)

Ability to control (3)

### **Altering life to fit self**

Acceptance of vulnerability (5)

Relationships (5)

Accommodation (3)

Occupation (4)

Managing illness:

Use of services (4)

Self help (4)

### **Negative impact on self**

Anxiety (3)

Depression (4)

Negative self image (6)

Loneliness (1)

### **Integration of positive and negative impact**

Impact on self of symptoms (5)

Impact on self of experiences (4)

Overall Impact on relationships (4)

### **Intervening Variables**

Effect of culture (2)

Effect of mastery (3)

Effect of social support (6)

Effect of social comparison (3)

## Appendix 8 - Examples of quotes and codes of one category

This includes examples of two quotes for each code that made up the category of 'Others becoming aware' in the first stage of adjustment, 'Becoming different'.

### **Others Becoming aware**

<b>Sub category</b>	<b>Code</b>	<b>Quote</b>
Becoming aware	1. Friends becoming aware.	a. ...and my friends were asking about me aswell cos they said that I was acting different like I wasn't myself (F7) b. Well I didn't tell anyone I heard voices but I think everyone knew that I was getting ill like my friends and everyone around me because I started acting different, not being myself (M5).
	2. Family becoming aware	a. ....cursing and shouting because I thought my neighbour was chucking at me but I don't know cos my brother came downstairs cos one time I was shouting so loud at nighttime and he said to me he didn't know who I was talking to. (M6) b. ...well my parents said I was ill.. (M5)
	3. Wider systems becoming aware	a. I make an appointment with my school counsellor and she said to me that they were going to throw me out of college because I wasn't attending so I left. (F7) b. ...my GP referred me to the surgery psychiatrist. (F9)
Action	1. Helpseeking	a. My family decided..well yeah they told me they wanted me to actually call the doctor and everything. (M1) b. My parents agreed. I wouldn't have been pushed into hospital if my parents hadn't agreed. (M3)
	2. Action to the person	a. Well because of what happened all the girls run away from me. If I'm in the kitchen, they're not in the kitchen. (F12) b. Well my mum used to come round a lot but I didn't appreciate it. She used to keep coming round like there was something wrong. (F11)

## **Appendix 9 – Interview Transcript**

## Interview

I: I'm recording the interview really so I don't have to write anything down but I might sort of jot a couple of things down to come back to or whatever. I suppose if you could just start by telling me something about your current circumstances?

P: My current circumstances... well last March, I'll need to go back to that.

Last March I moved out of residential care, the [REDACTED] which is in [REDACTED] and into my own flat.

And while I was in the [REDACTED] I was doing really well you know I was just seeing my keyworker there and getting on, and I was really excited about moving.

And then when I actually moved it all sort of came on top a bit, I started suffering some really bad anxiety and that, and I couldn't go out and I couldn't stay in and I couldn't do anything.

And em I ended up at the EPS and I wasn't admitted but they referred me to the day service here, that was in about June last year, I moved out in the March so yeah it was about June last year that it really came on top.

And em I've been attending the day service since then.

(Right)

I do em voluntary work twice a week at the [REDACTED] Carers Centre.

I: Oh right what do you do there?

P: Work in the office.

[REDACTED]  
On reception, on the phone, using the computer, meeting and greeting people.

I really enjoy that especially the meeting people part, meeting the carers and that, you know you meet some people who are really sort of like tough in the face of adversity and it puts into perspective like your own situation.

And em I've just started to do a few things with MIND, like I've joined the User Evaluation project.

The job that I do, the voluntary job that I do is also through MIND its part of their small jobs project.

I: Right, so you got it through them.

P: Yeah, and erm what else can I tell you about me now, erm my current situation em, I've got two children, a son of 19 who lives in [REDACTED] and a daughter of 12 who's currently skipping school (laugh, day off).

And em I live on my own except for when my daughters there half the week but apart from that I'm on my own.

I: Right, so she stays with you half the week.

P: Half the week yeah, half the week with her dad.

But we're in negotiations about changing that at the moment so I don't know what will happen there, it may change.

I: And has that been since you've been in the flat that she's been staying half the week?

P: When I was in the [REDACTED] she used to stay with me.

(Oh right)

P: Yeah I did, I felt like it was the cause of it and erm I started using again intermittently when I was in hospital.

I started getting someone to bring drugs up when I was in cos its really easy in [REDACTED] to have drugs brought in and to use you know.

I: To use on the ward?

P: Yeah when I was there there was a lot of drinking and drugging going on there, I don't know what its like now.

So the way I made sense of it was, I don't know how I made sense of it, one thing was to think you know if I like had the heroin back I'd be OK the other... the other, one of the other things I did was to sort of like, I don't know, it was, its hard to explain, but it was like surrender to it all you know.

Like stop sort of, stop all the denial about the fact that I wasn't unwell cos I was still, I was still half the time saying there nothing wrong with me I'm fine.

So one of the big things for me for coming to terms with it was actually finishing all the denial and surrendering the the fact that that I needed help.

I: That sounds hard to do?

P: Yeah, it was you know. It was especially hard to do on the ward in [REDACTED] because its you know you're surrounded by a load of people who are sort of like doped out of their brains and are just wandering around like zombies.

You know the most you ever get out of anyone up there is got a fag, got a fag, got a fag, you know.

And I remember being really scared thinking OK if I'm ill is that the only choice that is left for me to remain ill or to become zombie like like that.

I: So you were watching other people and wondering whether you were going to end up like that.

P: That's it, like that you know.

Like I watched one guy [REDACTED] he came into hospital the same time as me and in the weeks that I was there, he was about six foot tall and must have weighed about eleven and a half stone when he came in but he went from being talkative and playing scrabble and all that. He must have put on about a stone and a half and done nothing but sit in front of the telly after a few weeks.

You know I saw the change in him, I didn't notice any change in myself though there must have been some, but I noticed...

I: Seeing it going around you.

P: Yeah, but there must have been a lot of change in me because I was being medicated but I couldn't see it in myself.

I: No, yeah its harder to see in yourself.

P: Yeah, but I could see it in everybody else.

I: Yeah, how did the doctors and nurses at that time make sense of your experiences to you?



I: Would you, I was just sort of thinking about how having the mental health experiences you've had, how they might have changed some of your relationships so like with your mum?

P: Em... They've brought us a lot closer together.

The relationship with my mum, I'm now closer to her than I've ever been.

You know I mean she's... when I was using it was a very one way relationship, I would just take, take, take, I'd steal off her, I'd borrow money off her, I'd take me son round there and say I was going out for half an hour and disappear for two weeks, all that sort of thing, it was a really one-sided relationship.

Then when I first fell ill, it was she was really sort of supportive you know, she was the first person to take me to the GP, she used to come with me to see the psychiatrist, she used to come to me CPAs.

I: Right, so she was really there...

P: Yeah, she'd always visit me every day in hospital.

If I was in hospital she'd be there every day regardless you know, whatever the weather, whatever the situation in the rest of the family, she'd be there and erm ... since I've got off drugs and my mental health's been a lot more stable I've been able to give things back.

Like when she's been ill cos she suffers a lot I've been able to say like stay in bed, I'll do your shopping and like she wanted to go on holiday but she couldn't leave my dad so last year I said to her I'll stay with dad you go on holiday, and let her go, just things like that.

I: Being able to do things for her..

P: Yeah, so yeah we're much much closer and my relationship with my husband, well my ex, well we're not divorced but we're separated.

That's that's 100% improved as well you know and I think the change is in me not in these other people.

I: Right, what kinds of changes?

P: In me?

I: Mmm.

P: Er... I'm a lot more self aware I have managed to do some talking therapy and some counselling and stuff like that so I'm a lot more self aware.

I'm a lot more tolerant of people and a lot more honest.

Er... you know like I never used to be able to admit I was wrong about anything and now I can I'm quite, I'm not backward about coming forward and saying oh I was wrong about that and I'm sorry.

I: Mmm, and that's a difficult thing to do as well isn't it.

P: Mmm, and I've spent a lot of time over the last couple of years saying sorry for things you know, not just sorry for things that have happened now but also sorry for things that I've done in the past to people.

Like I'm sorry for [REDACTED] that's my daughters dad but he was coming off of heroin as well but I just left him with [REDACTED] and went into rehab you know.

It was easy for me I removed myself from everything, went into a safe house and got clean.

And I left him in London coming off of heroin with only NA meetings if he could find a babysitter so that he could get to one you know.  
And a young child of three years old who started to act out badly cos her mum wasn't there.  
So I'm sorry for that you know.

I: Yeah, so you were apologising for things, but he was clean wasn't he you were talking about him...

P: He's clean now, he's clean now. At the time I first went into treatment he was he was clean he was just off a methadone programme but he was in bits.  
You know he was physically clean, there was no drugs in him but mental he was just in pieces you know....

I: Has having mental health problems effected your relationship with the children?

P: Yea, yeah my son who' 19, lived with me until he was about 8.  
He left not because of mental health problems but because of drug problems.  
But he went to his dads and erm for Easter and at the end of the holiday his dad rang up and said he doesn't want to come home  
And I didn't believe him but [REDACTED] rang up and he said I don't want to come home mum you know, I can't take it anymore, you're always fighting with Trevor my partner and you're always out of your head and its much nicer here.  
So I got really upset and we ended up in a big court custody battle and then on the day of the actual hearing the custody hearing, [REDACTED] that's [REDACTED] dad brought [REDACTED] to court with him.  
And before the case was heard [REDACTED] said can I speak to you on your own and I said yeah and he said I don't want to mum he said but I will I'll come home as long as you promise to stop all this court stuff.  
When he said that to me I just fell to pieces you know, I thought what am I doing to him you know.  
It just made me realise for the first time ever that sometimes loving someone isn't about keeping them its about letting them go.

I: Being tough.

P: Yeah, and now the effect that my mental health has had on him is that he finds it very difficult to talk to me about his problems.  
I've talked to him about this, he thinks that if he comes to me with a problem its going to upset me so much that I'm going to become unbalanced.

I: Right, so he'll keep it from you.

P: You know so he only talks about nice things.  
Although that's got better over the last 12 months, I've sat down and I've said to him I'm stable you know I can cope with things if you need to talk to me about anything and he talks to me a bit now.  
Over the last 12 months I've found out that he's pretty screwed up you know, he's...

I: He's got some problems.

P: Yeah he's got some problems of his own.

And I think the effect that my mental health has had on my daughter is more understanding of people that are different within the bounds of what I would call normality you know. Because she used to come and stay at the [REDACTED] and it's sort of like six women living in a flat all with their own problems and sometimes people would be OK and at other times they would be maybe not so OK, but she got...

I: She got a wider view.

P: Yeah, she got a wider view so she's, I think it's made her a bit more... a bit more sort of, I'm not saying she's wonderful you know.

Like she's still, she's got a friend called Schiz, and I say to her don't you know that's short for schizophrenic it's a bit erm... out of order, I can't think of the word I want to use but you know like to use it as a joke like that.

But she don't see things like that but actually with people she's quite sort of....

I: So it's had a positive effect really.

P: Yeah, yeah it has. Not the drug taking but the mental health.

I: Yeah, yeah. You were saying earlier about schizophrenia, did you receive a diagnosis of schizophrenia?

P: Yeah I did from Dr. [REDACTED] about 1995 but I think that every other Joe Bloggs who goes through there is diagnosed schizophrenic so I don't know....

I: Can you tell me how that happened, how he did it?

P: No probably not... I'm trying to think..

I: It's remembering all these things isn't it.

P: Yeah..... I think, I think what must have happened was he made his diagnosis, never told me about it and then one day it just came up during an appointment..

You know like he said something like oh well erm as a schizophrenic these symptoms are quite common and I remember thinking oh so that what I am (laugh).

I: Thank you very much!

P: Yeah so I don't think ever actually told look we're giving you a diagnosis of schizophrenia, this is why because you've got this this and this symptom, I don't think I was ever told like that.

I: So you think it just sort of came up.

P: It just sort of came up during an appointment as far as I remember.

I: Mmm, how does it feel to learn something like that in that way?

P: Em..... well at first I I it sounds awful but I thought they must have got it wrong I didn't think I could be a schizophrenic.

Because the only schizophrenics I'd ever heard of were sort of headlines in the newspapers about about supposed schizophrenics who'd gone and stabbed someone or killed someone or burnt someone or done you know something antisocial or unlawful or whatever and I thought well that's not me, that that that can't be me.

And em so I decided to do a bit do a bit of reading, reading about it.

And em I read about hearing voices, psychotic behaviour, paranoid behaviour and all that and how they bunged all that under the heading of schizophrenic and that.

And I decided really they could call me what they wanted, I didn't think it was a very useful label, its not like saying someone's got German Measles, oh you can treat it with this.

I decided they could call me what they wanted.

I: And that was their view.

P: And that that was their view and I've got my own view.

My own view is that I that whatever, you know like with my mental health problems I fall in the realms of normal as do hundreds of thousands of other people who have mental health problems you know.

The spectrum of whats normal in life goes from here to here (*indicating large space*).

You know and millions of people fit into it, we're all different but we're all normal you know.

I don't think labels like schizophrenic help anybody.

I: What harm would you say its done you, can you say?

P:.....Yeah the diagnosis of schizophrenic..

I: Yeah, has it harmed you?

P: Em when I first before I started reading up about it and decided that I wasn't going to have it for myself it made me feel really sort of like a hopeless case.

Oh I'm schizophrenic well that's it then.

You know like there was nothing I could do about it, there was no way I could get better, I just had to wait until I turned into a knife wielding crazy, which was obviously what happened.

You know I thought that the disease progressed in some way and that eventually I would end up as some axe wielding maniac because that's what I thought schizophrenics did so I think it did do me harm.

I: It sounds quite harmful.

P: And especially with no one to explain why I was getting the diagnosis and you know whether it was, whether the idea was once a schizophrenic, whether it was an illness you could get over, whether it was like a state of mind.

I: So there was no information given but you went out to search for the information.

P: Yeah I got some information from [REDACTED], I got some information from the [REDACTED] and the [REDACTED] but never from like the NHS, mental health service resources, never from psychiatrists or anyone.

I: So what are the things that have helped you to cope?

P: .....Despite what I say about Dr. [REDACTED] the medications helped me, it has had an effect (that's good) it has had an effect it did stabilise me.

I'm not sure I need to be on it six years later but that's something I have to sort out for myself.

But erm and what has helped me to cope.....

The thing that made the biggest difference to me was moving into residential care at the [REDACTED] and erm

I: What was helpful about that?

P: Erm just having somewhere where I could learn with support to get on with the the erm....the idea of just daily living, to get on with the idea of daily living, you know.

I: Right, it was somewhere you could do, just do things.

P: Just do things you know like get up in the morning, make coffee, watch telly for a while, read a book but in the knowledge that there was always someone there if you didn't feel right you know if you felt unwell.

And through the [REDACTED] they helped me get a lot of the talking therapy that I had. They organised for me to go to [REDACTED] and I went to Family Counselling in, I can't remember the place that was in [REDACTED] as well.

And erm I joined a Kanas group, a group of people who hear voices, and we meet and talk about what its like.

I: And that was useful.

P: And that was useful yeah that was useful.

And erm .....So the medication has stabilised me but all the other stuff has helped me to improve my quality of life you know.

Just counselling therapy, people being there, support, occupational therapy you know people showing you how to occupy your time and keeping busy.

Doing something worth while and not to just sit and wonder you know cause I used to when I was first ill I used to sort of sit and really think hard about how mentally unwell am I today.

Like today is the 2<sup>nd</sup> March what would I say about my mental health?

Am I being very irrational, am I being slightly irrational, am I paranoid?

I: Oh gosh, yeah.

P: And I'd sit there for hours wondering how I felt instead of just getting on and doing stuff.

I: And its very difficult to answer those questions as well isn't it.

P: Yeah, you know if your thinking is irrational you don't necessarily know its irrational so how can you answer your, how can you answer questions like that.

But erm.....yeah I would say that all the talking stuff has been the most help but I don't know if I could have done it if I hadn't have had the drugs to stabilise me in the first place so maybe they go hand in hand.

I: Yeah I was wondering as well how you got from the point, you were saying there was a point where you were feeling hopeless and sort of helpless and that sort of thing and that now you've got your own explanations for things, your own views on things and you're sort of managing yourself, how you got from?

P: How I got there?.....

Erm..... I don't know.

I: No, Its hard to answer?

P: I guess em.....just informing myself as much as I possibly could about about my own illness you know and finding out about it you know.

And reading about how other people coped with it you know.

I saw a documentary on the telly you know and one of the people on it was [REDACTED] and em he works at [REDACTED] n now and I was amazed at the way he coped with hearing voices.

When he said I've got this little statue and when I hear voices I take it somewhere and hide it in the house you know and that helped, I don't know whether it took the voices away or helped him deal with them at that time.

But that's what he used to do and I was thinking wow you know you can hear voices, you can have irrational thinking, you can have anxiety and you can lead a normal life.

You know so it was a gradual sort of process of realising that I wasn't like you know there was no need to write myself off, that I could actually do something you know.

By watching other people around and by reading and by moving into the [REDACTED] cos that is the one major thing that has happened to me that has made the difference.

I: Its good isn't it that you had that experience.

What would you say has been unhelpful?

P: Unhelpful...

I: In that process..whats kind of hindered it?

P: ..... I can't think of anything to be.....

Em, I can't think of anything that's been really, I would say yeah that has set me back, em.....there have been things that I've done that I think have made no difference but they haven't actually set me back.

I: Right.

P: Like I saw a Psychologist for about 8 weeks, 2 weeks of assessment and six sessions on dealing with anxiety and that.

And maybe I you know maybe I could have got more out of it if I'd of put more into it but like I said before I'm a bit intimidated by authority figures.

And you know like he was sort of telling me to deal with my anxiety by occupying myself by taking up macramé and things like that..

I: Right, is that the...

P: Tying knots to make potholders out of, or jigsaw puzzles, that was just one of the things he said, jigsaw puzzles, macramé, playing the guitar.

And em I did stick it out for the whole 8 weeks, I went every week but I don't think it was helpful but it wouldn't it didn't hinder in any way.

I: It just didn't help.

P: It just didn't help but I don't think theres anything I can put my finger on and say that has had a negative effect on me. No I couldn't.

I: Right. And you were saying as well the way you think about its changed, when you first went into hospital you thought the cause was coming off heroin at the time, what do you think now, is that the same, do you still think that or?

P: That the cause is..no..

I: That's changed..

P: No, I don't know.....I dunno exactly, I think it stems from childhood and I don't know whether...whether, em, I was born with a predisposition to mental health problems or whether it was because of the way I was brought up although neither my brother or my sister suffer from mental health problems.

But I can remember from a very young age my mum saying oh don't upset Sally she's the sensitive one.

I: Right, mmm.

P: You know, so I tend to think it stems from childhood you know.

I: That there were some difficulties in childhood.

P: Yeah, yeah like my dads an alcoholic and its not surprising that I'm an addict.

My mum is just the most anxious person I've ever met and yet she deals with it completely on her own and that.

She's got her own way of dealing with things you know and she is one of the most worrying anxious people I've ever met and I think I get that from her.

I: Yea, mmm

P: And em I'm not exactly clear I couldn't put my finger on it and say well this event in childhood led to me having this but I think it goes back that far.

I: So your views on the cause of whats happened have changed as well.

P: Yeah, I'm not saying the drugs had nothing to do with it, they might have had something to do with it but..

Tape change.

I: Yeah, right so we were just saying the roots of it were in childhood (yeah). Going back again as well we were talking about the effects that mental health problems have had on relationships. I was just wondering more generally sort of on other things in your life, what were the kinds of effects?

P: Has mental health had?

I: Yeah.

P: Em.....its made me more isolated.

Em..I find it hard to communicate with people outside the mental health circle you know.  
Like I can communicate with other users of the day service or MIND.

I can communicate with you as a professional.

But when it comes to social things and that I find it, you know I think I don't what small talk is.

And then I'm so used to sort of like.....the honest sort of way that we talk to each other around here that I find it hard to get involved in a lot of the bullshit, the social rituals that go on.

You know if someone says to me oh how are you?

Well if some one downstairs says to me how are you, I say well I'm not so well today

I: Give an honest answer.

P: Yeah, whereas if someone outside says how are you, you just say fine, sometimes I forget that.

You know so when someone says to me how are you, I sort of say well actually...*laughing*.

*I: Laughing*

P: And its not right, you know its not appropriate.

So its made me more isolated you know I find it hard to communicate with people.

I find I think people that know I've had mental health problems find it harder to communicate with me.

I: Right, so it's a two way thing.

P; Yeah, like I'll be walking down the street with my mum and I'll be standing right next to her and I'm taller than her you know I'm not insignificant in size and like and they'll say and how's [REDACTED] to my mum.

I: Oh no.

P; And I'm standing there you know and I think, right you could have asked me so I think that people that know you've had mental health problems, there's still a lot of stigma attached to it. Its made me isolated, I've found it hard to communicate, its made me, what was the question?

I; It was just asking about the effect that it had on your life.

P; Oh yeah em.....its made me a more diligent person, its taught me perseverance.

I: Right, yeah, Like working at things do you mean?

P: Yeah, its taught me, made me more diligent, taught me about perseverance.

You know like things that I used to find easy, I now find really difficult and to do them is an achievement for me and I try to do them as often as I can, like travelling on the bus or leaving [REDACTED]

I; They're things that are hard.

P: They're things that are hard and .....er and I persevere more now with things like that than I would of in the past.



And its made me more, made me more politically aware, politically conscious of things. Not on a great sort of wanna to change the world party political level or anything like that. Just just from a mental health service users point of view, I'm interested in in in the politics of that and I'm interested in helping to do something in making things better whereas previously I was never really interested in anyone outside myself.

I; Mmm, its given you a wider view, as well as your daughter, a wider perspective.

P; Mmm, yeah, yeah.

I; How do you think life would have been different without mental health problems?

P: I'd probably be erm still using heroin or dead from a heroin overdose.

I probably wouldn't have a relationship with either my children or my mother.

Its weird that something so so distressing like...em mental health problem can in some way have such positive effects on your life.

Because it makes you re-evaluate everything, it makes you realise whats important, that's another thing its done for me is its helped me realise the things that are important which is relationships, and honesty and you know self esteem and things like that you know.

And if I hadn't have fallen ill I don't think I would have been in a very good position.

I: Right, so its interesting that something which is as you said distressing can have such positive effects.

P: You hear about it with other illnesses like people who get cancer, or people who get HIV suddenly become really health conscious and change their lives around and become....

I: Right, so in a similar way, you've changed things.

P: Mmm, yeah.

I; And what about plans for the future are they?

P; My plans for the future eventually, I've got a five fold plan *laughing*.

No eventually I'd like to go back to work, not doing what I did before which was working with children in an adventure playground.

I: Oh did you, oh right.

P: I used to work for [REDACTED] council, I wouldn't like to go back to doing that.

I would like to do something, something, something, probably end up working in the voluntary sector or something like that for a charity, maybe within mental health or the drugs service, drug misuse service.

Em, the future, and I'd like to think I could come off my medication at some point you know that's a big one for me, I've got a CPA next Wednesday and I'll bring it up again you know.

I'd like to think I could come off my medication at some point.

I'd like to think I'm aware enough of myself to be able to come off it and then to know if I was getting to a point where I would need it and to be able to take it.

I: Yeah.

P: And to be able to take that again, you know I think I'm aware enough, I think I've got enough insight for that you know.

And em to get a job, come off me medication.....

Just to keep working on my relationships with people like especially my children.

And em..... to learn to become a member of society as a whole rather than just just a member of this mental health service user subculture.

I: Mmm, mmm. So you sort of want to go back into the wider...

P: Yeah, yeah not that there, it's a really cosy place this.

But for me I feel like and whatever other people decide, but for me I feel like I'd like to participate in....

I: Well in both is it?

P: Yeah, yeah in both. I think I would.

I: That's been really useful, let me turn this off...

The end.

## Appendix 10 – Excerpt of coded interview transcript

I represents interviewer, and P represents participant. Coding for appropriate segments of text is represented in *italics*, and each coded segment forms a new paragraph. Segments of text unrelated to the research questions are not included, but represented with ellipses.

I: How do people in hospital explain your illness to you?

P: They haven't helped, they haven't helped not really. I've always, they've always asked me questions and wanted me to come forward with information, doctors came in asked me all sorts of questions, asking me everything, and me having to explain my own illness. *Limited explanations*

No one really helped me, I had therapy groups that helped more than anything else because at least you got a chance to talk about yourself, em and there was some kind of response.

*Importance of talking therapies*

I: You got something back..

P: I got something back but especially last time I went in with, I call it schizophrenia when I was hearing voices and my thoughts were all over the place, I never really, I am diagnosed that, schizoid depression, so...

I: You said you called it schizophrenia, have they talked to you about that?

P: Well noone has really *Limited explanation*.

.....Last time I couldn't help myself, I was so ill, I didn't know what was going on. *Lack of understanding*.

I just, I tried to get books on it but I had a book, it was too complicated, it was just too in depth so I didn't read it. I was going to get another one but I didn't in the end. *Gathering information*.

I: It sound like you've had to seek stuff out for yourself..

P: Yeah, yeah. I did try to get books on things and everything. *Gathering information*.

Its difficult. I have got it written down and I can actually read through what happened at that time, it helped to write it down *Role of reflection*.

I: I was also wondering about the roles of other people, maybe your parents but also other people in the illness you've had and the experiences you've had.

P: My parents especially my mother are very aware of my illness, like she's always been there for me *Effect of social support*.

....And my sister helps me aswell. She when I've been ill shes tried to talk to me to calm me down. *Effect of social support*.

But I've been finding it a bit stressful with my sister here because shes very outgoing and shes always on her mobile phone and shes always going out and going to work and I find her a bit of a threat in a way. A threat in that I'm not jealous of her its just I feel cos my lifes not going anywhere *Effect of social comparison*